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# The ethical accommodation of patients' religious beliefs in healthcare: a care respect framework prompted by examples from modern Paganism

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#### **Abstract**

Conflicts of values arise between the values of healthcare staff, and the values of some religious patients. The reasons why, and the extent to which, patient beliefs and values ought to be accommodated has been a feature of the ethics literature for some time. Despite this, some patients still experience difficulty in having their religious and spiritual needs met, and some staff are still reluctant to engage with religious and spiritual issues. Thus, the compassionate and respectful care the NHS claims as a value is not, in some instances, being met.

In this thesis I put forward an alternative way of conceptualising the need for and the limitations of accommodation for the religious beliefs of patients. I draw on Dillon's conception of 'care respect', a feminist-ethics-informed fusion of respect for persons and care ethics. Using the foundation of care respect, I explore and critique justifications for accommodation. I argue that because a person's beliefs are an essential part of them, we have a general obligation to accommodate those beliefs if we are to be serious about respecting persons. This obligation to persons also imposes important limits on what accommodation is permissible.

Much of the literature has focused on the Abrahamic faiths. Systems of weighting for and against particular accommodations are shaped by that particular understanding of what religion is. They may be exclusionary of less well-known faiths. I address the issue of whether the beliefs of modern Pagans are adequately supported by current options and find that they are not. I therefore use care respect to structure a weighting system that balances the conflicting obligations in any particular case, including those where the patient's religious beliefs are Pagan ones.

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## Contents

Abst	tract	ii
Ackr	nowledgements	iii
Tabl	le of Figures	vii
1.	Introduction	1
1.1	Inspiration	3
1.2	2 The Thesis Question	6
1.3	Development of the theoretical foundations of the Thesis	6
1.4	ı Methodology	8
1.5	Contextualising the Thesis: religious beliefs and healthcare	10
1.6	5 Thesis Structure	22
2.	An introduction to religions and Paganisms	29
2.1	Religion in general	30
2.2	2 Paganism – an introduction	53
2.3	3 Specific Pagan paths	59
2.4	4 Paganism and contemporary religion	76
2.5	5 Concluding remarks	78
3.	The impact of religious beliefs on healthcare	8o
3.1	Religion's impacts on health care	81
3.2	2 Life	83
3.3	3 Death and disease	86

3.4	Religious beliefs and the nature of the body	90
3.5	Religious belief and mental health	96
3.6	Relationships with the divine and the other	101
3.7	Concluding remarks	110
3.8	Case studies	111
4. Cai	re Respect for Persons	121
4.1	What it is to respect	122
4.2	Recognising patients as persons	128
4.3	Caring about patients as people (feminist ethics)	138
4.4	Care respect (CR) – a special type of respect	146
4.5	Respecting (persons with) religious beliefs	152
4.6	Care respect and religious beliefs- concluding remarks	157
5. Au	tonomy, beneficence and care respect	.160
5.1	The concept of Autonomy	162
5.2	Religious belief and threats to autonomy	. 166
5.3	Beneficence: doing good in medical ethics	185
5.4	Concluding remarks	. 198
6. Lin	nitations on the accommodation of religious belief	203
6.1	What limits does CR impose?	.204
6.2	Toleration	.209
6.3	Harm to others	215
6.4	Legal limits	. 222

6.5	The limits of possibility	3
6.6	Concluding remarks24	4
7. Ba	llancing conflicting obligations: weighting system approaches248	3
7.1	Meeting the demands of CR in the accommodation of religious belief249	9
7.2	The origins of the weighting systems – Wreen and Orr and Genesen25	2
7.3	Buryska250	5
7.4	Bock268	3
7.5	Concluding remarks282	4
8. A	Care Respect approach to accommodating the religious beliefs of modern Pagan	S
	28	7
8.1	Towards a weighting system that works for Pagan patients	3
8.2	A new 'weighting system'292	2
8.3	Taking people seriously31:	2
8.4	Concluding remarks32	3
9. Co	onclusion328	3
9.1	Religious beliefs are important330	Э
9.2	Religious beliefs impact on healthcare, and religious believers may be poorly served 33:	2
9.3	Care Respect addresses important aspects of the person which support the importance of	ıf
religi	ious beliefs334	4
9.4	Autonomy and beneficence are related to CR	5
9.5	CR supports limits on the extent of accommodating religious beliefs in health care	e
	338	

9.6	CR's requirements	340
9.7	Existing weighting systems for accommodation are inadequate	340
9.8	A CR approach can be used to shape a framework for accommodation	342
9.9	Care Respect and the five criteria, application to the Pagan cases	345
9.10	Investment in staff training is required by CR	347
9.11	Further work	349
9.12	Final comments	350
ю. В	ibliography	353
Legal	references	353
Cited 1	Publications	354
	Table of figures	
Figure 1	Jigsaw worldview (Martin Winchester after DeWitt 2010 p10)	44
Table 1 V	World religious adherence	36
Table 2	Religious following England and Wales 2011	36
Table 3	BSA Religious Affiliation in the UK 1983 - 2016 (NATCEN 2017)	36
Table 4	Pagan Following in the UK	56

### 1. Introduction

In the healthcare sphere (as in the world more generally) the worldviews and values of patients and staff can differ widely. This generates a conflict, particularly between the values prioritised in UK healthcare organisations, and the values prioritised in the worldview of some religious patients. The reasons why, and the extent to which, room can and ought to be made for patient's values (the extent to which they can be accommodated) has been a feature of the literature for some time. Despite this, some patients still experience difficulty in having their religious and spiritual needs met (Care Quality Commission 2018, Clayton 2010), and some staff are still reluctant to engage with religious and spiritual issues. As a result, as well as experiencing unhappiness, patients are potentially put off from seeking care in an environment which may be judgemental and unaccommodating. If securing health for others is a value of healthcare, then presenting those others with barriers to health and well-being by not accommodating their values is to fail in achieving a moral end.

Religious beliefs form a profoundly important role in shaping the identity and morality of the person who holds the belief. However, much of the literature around the accommodation of religious belief has involved adherents of the Abrahamic religions-Christianity, Judaism and Islam. Because of the recognition afforded in the West, to these better-known religions, Paganism (as a much smaller and more recent religious phenomenon) is frequently misunderstood, trivialised, and viewed with suspicion. As a result, those with Pagan beliefs are underrepresented in the discussion. Although Paganism differs from what is often thought of as 'Religion', adherents of Paganism are entitled to the same accommodations. Pagan beliefs perform the same, identity and meaning giving role for the believer as do the more well-known Abrahamic beliefs.

20

Often, the consensus is broadly that religious beliefs and other patient values merit consideration, primarily for reasons of respect for liberty, but also because it may be beneficent to do so. Autonomy-based and beneficence-based principles (Beauchamp, Childress 2012) retain an important role in taking people's beliefs seriously, and justice-based ones often demand a limit to such accommodation. However, overly demanding levels of rationality, biomedically restrictive concerns of beneficence, or inappropriate loci of justice fall short of meeting patient needs.

In this thesis, I put forward an alternative way of conceptualising the need for, and the limitations of, accommodation for the religious beliefs of patients as a means of addressing this difficulty. Using Robin Dillon's (1992) 'care respect' approach as a basis, I argue the locus of our obligations to those with religious beliefs is respecting and caring about the person they are. Persons are thinking, feeling, interdependent and embodied beings. Religious beliefs, in those that hold them deeply and sincerely, are an integral part of their being the person they are, shaping their understandings, identity and relationship with the world. I argue that because the person we wish to respect does not exist without their beliefs, we have a general obligation to accommodate those beliefs if we are to be serious about respecting persons.

Several authors have additionally proposed criteria which are aimed at weighting and balancing conflicting ethical principles in individual cases of religious claims for accommodation (Buryska 2001, Bock 2008). The criteria balance the need to accommodate with the need to impose limits. Currently these criteria disadvantage Pagans because of their emphasis on traditional communities. Using knowledge of Pagan belief systems and the concept of 'care respect', as well as legitimate limits on accommodating religious requests, I

30

propose an improved weighting system, based on care respect that identifies when such requests ethically should be granted, and when they should not.

#### 1.1 Inspiration

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In 2007, I managed to sever a minor tendon under circumstances best described as comedic. The next morning, I was in hospital at 7am waiting for surgery to fix the injury before it became unfixable. Problematically, it was the 21st of December, the day of the Winter Solstice. As a Pagan, it is an important celebration for me, and I had organised a gathering that evening. It was, in its way, as important and meaningful for me as Midnight Mass might for those of strong Christian spirituality. Celebrating the Winter Solstice reflected core beliefs around the significance of transition through the seasons, that life and light eventually break through the darkness. As a Pagan, I had an obligation to both mark the date and share the time with friends. It also had an additional deep personal connotation as it was the 3rd anniversary of the date I'd adopted a Pagan name as part of a public acknowledgement of Paganism as my religion – my Pagan birthday as it were. No one wants to be in hospital for unexpected surgery at any time, but I really didn't want to be there any more than someone for whom Christmas is *spiritually* important would want to be there on a holy day.

From the outset, it seemed that those concerns were dismissed as meaningless. Pagan, for example, wasn't even on the 'religion' option of the information form. I was anxious to know when the surgery was scheduled because I wanted to get out (it was, after all, a day case) as soon as possible. I was told it didn't matter if the list overran as they'd keep me in until the next day. I tried pointing out I was a Pagan, and that in effect I was in hospital on the equivalent of Christmas Eve running into Christmas day. Surely my concerns were

understandable. "But it's *not* Christmas day," said one nurse. "Oh," said another, blankly. "The surgery is what's important, though." I tried explaining how important it was that I should be seeing loved ones and friends, some of whom had come a long way, not all of whom I could contact to stop them coming. "They'll understand." They would have, but it wasn't about whether they would understand, it was about my commitment to honouring a religious belief, one that said I should appropriately mark an important day with ritual and the provision of a feast. All I wanted, I suspect, was for someone to spend five minutes with me talking about the fact these concerns were bothering me, that my Pagan belief system was legitimate and worthwhile as a motivation - for someone to recognise that being in hospital on December 21 wasn't the same to me as being in hospital any other day. I wasn't frustrated by 'not being able to go to a party' as one nurse commented, I was frustrated

In the end, the closest compromise that could be reached was I *might* be allowed to leave if they didn't do it that day, but only on the grounds of practicality. I was pretty much resolved to discharge myself, but as it happened, the surgery did get done that day and I eventually made it to my celebration. I never, however, forgot how blankly I was treated that day.

Looking back reflectively on the situation, I see several places where my Pagan beliefs intersected with the care I needed. It was not a case involving life and death, such as those characterised by Jehovah's Witnesses refusing blood transfusions, or those who demand extreme life prolonging measures. Having already studied medical ethics and worked in various health-related and medical teaching environments, I knew that many people

90

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80

because it wasn't 'just' a party.1

<sup>&</sup>lt;sup>1</sup> There was also much amusement to be had from the staff's reactions to the fact I lectured in medical ethics but that's a different story, I wish I could remember the name of the anaesthetist, he was 100% the best person I spoke to that day.

unexpectedly in hospital are bewildered and confused by what's going on regardless of their religious or areligious mind-set. Completely removed from any consideration of religious beliefs, simple communication about what was happening and when was generally appalling. I understood that any ward for short-notice operations is a hectic place, (particularly with winter staff shortages) and there is no easy way to predict when a slot will happen, due to not knowing what each case will find, and that indeed 'everyone here wants to know [when their operations are happening]'. I understand that the staff are busy, pressured by time constraints on what time they can spend and that good physical outcomes are a reasonable focus for medical priority. The time poor and pressured environment is ultimately in need of additional resources to fulfil caring obligations whether religion is involved or not.

In my case, however, what I still found dehumanising was the ignorance around my belief system that also translated into a general indifference. If it *had* been Christmas day, it would have been recognised that that was a particularly nasty day to be in hospital. Even after I had said 'this is the equivalent of being in hospital on Christmas day for me' no one actively or openly acknowledged that. I had explained that there were important spiritual issues at stake, but this was perceived largely as an irrelevance. Were I, *mutatis mutandis*, a Christian (or even a bank holiday loving atheist), and it were Christmas day, the staff would have responded differently.

This experience made religion's intersection with healthcare become an interest, and why I chose Paganism as the group with which to look at how we account for religious beliefs in healthcare. As I started to research the area, I found reports from other Pagans (and members of other religions) being side-lined, being considered delusional, misunderstood and even bullied within healthcare because of the nature of their beliefs. Something was

100

going wrong with the way people with religious beliefs, particularly Pagan ones, were being seen in healthcare, and it was leading to people being treated badly. Given that what hurt most was that things that were key to me, part of the things that made me an individual, my obligations and 'ground projects', were not acknowledged let alone understood, I focused my attention on why such rejection might matter ethically and whether it could be practically addressed.

#### 1.2 The Thesis Question

120

This thesis is located within a healthcare ethics framework. The thesis has a three-fold task; to establish whether Paganism ought to be treated in the same way as other faiths, to consider the ethical issues raised by conflict between the values of patients with religious belief and those of healthcare providers, and then to propose a methodology that gives proper weight to each issue. The overarching question, to which these examinations are applied, is *how can we ethically accommodate Pagan religious beliefs in the NHS?* 

#### 1.3 Development of the theoretical foundations of the Thesis

The approach I take to accommodating religious belief is developed from a conception of respect for persons termed *care respect* proposed by Robin Dillon (1992a). Care respect (CR) fuses elements of care ethics, such as it being *particular* and *personal*, combined with respect for autonomy. Persons are constituted by both rational facilities such as moral agency (Beauchamp 1999) and by their interests as interconnected (Code 1987b) and feeling, experiencing beings (Singer 2011, Korsgaard 2007). CR grounds ethics in the recognition respect (Darwall 1977) of both features of persons. Thus, to ignore what makes a person the particular person they are fails to accord them the respect they are due. Given holding

particular religious beliefs informs what it is to be that particular individual person (Benjamin 1990 pp.92-93), accommodation is necessary in order to be serious about respecting persons.

The interdependence of persons, rather than the independence represented by classic senses of autonomy, is a feature of feminist care ethics approaches. Much of the literature on accommodating religious beliefs has been around respect for autonomy (in particular with respect to capacity),<sup>2</sup> and much work on feminist ethics has been done with respect to medical ethics, <sup>3</sup> this particular combined approach has not been applied to the question of religious belief accommodation.

Additionally, ethical approaches to religion in healthcare have not been previously discussed with relation to the Pagan population of the UK; there is also little previous work on Paganism in healthcare more generally. This work thus adds to the growing body of Pagan focused literature in an environment where numbers of people identifying as Pagan are increasing (Office for National Statistics 2013, Pitzl-Waters 2013). The work does not only apply to Paganism, however. As the important element is the role played by some types of belief (which may be religious or secular) in formulating the nature of the person who holds that belief, and not the belief itself, the approach can be usefully applied to many areas of

140

<sup>&</sup>lt;sup>2</sup> For example; 'Should informed consent be based on rational beliefs?' (Savulescu, Momeyer 1997), 'Paternalism in the Name of Autonomy' (Sjöstrand, Eriksson et al. 2013a), 'Autonomy, religious values, and refusal of lifesaving medical treatment' (Wreen 1991), and 'Tales publicly allowed - Competence, capacity, and religious belief' (Martin 2007). 'Rationality and the refusal of Medical Care' (Stauch 1995) reflects the legal positions.

<sup>&</sup>lt;sup>3</sup> For example; 'No Longer Patient' (Sherwin 1992), 'Choice and control in feminist bioethics' (Dodds 2000), 'Compassionate respect, a feminist approach to medical ethics and other questions' (Farley 2002), and 'The ethics of care: a feminist virtue of care for healthcare practitioners' (Tong 1998).

personal belief and value systems that may involve ethical commitments on the part of individuals.

To assist in assessing claims for special accommodation on the grounds of religious belief, I introduce a new variant of a 'weighting system' arising from CR, which treats Pagans as equal to other religious groups, as well as expressly considering the wellbeing of the patient within a 'weighting system' framework.

#### 1.4 Methodology

Medical ethics is a subset of the broader category of healthcare ethics. There is no single agreed methodology within either, but both are generally considered normative disciplines. This thesis represents an analysis of some existing ethical approaches to accommodating religion in healthcare, broadly applying Dillon's CR concept, to see how fairly they apply to Paganism. I sourced published work on the accommodation of religion and on Paganism, then applied it to the UK NHS and UK Pagan context. This included identifying the ethical justifications for accommodation of religious belief in healthcare, forming an understanding of the existing approaches and examining for lack of coherency with each other and other ethical values in healthcare. The process shows the flaws of existing systems and enables me to build reflectively on the strengths whilst addressing the failings.

As few cases are documented regarding Pagans, In chapter three I make use of several 'constructed' cases -those which have not themselves happened but are based on relevantly similar examples. In particular they draw on cases involving Jehovah's Witness' refusal of treatment (Tierney, Weinberger et al. 1984, Elder 2000, Ridley 1999), concerns about the ingredients of medication (Sattar, Ahmed et al. 2004, Enoch, Shaaban et al. 2005), the concerns of Pagans within healthcare (Miller 2011, Hathaway 2006), and personal

experience. The cases in chapter three include a commentary highlighting other references. Using the plausible, hypothetical cases illustrates ways in which Pagan beliefs may intersect with health care. This is a commonly used methodology for exploring the impact of particular ethical considerations in a context related to the area of discussion.

Balancing and revising case examples and theoretical approaches in this way enables me to develop a reflective equilibrium (Nichols 2012, Daniels 1996) regarding the question of accommodating religious beliefs. Understanding of both practice and theory allows a change in approach in how religious belief is accommodated that can be used by practitioners to improve the quality of care of patients. This is used in developing a system that balances the ethical obligations by giving weight to one or another principle (Beauchamp, Childress 2012 pp.20-24) in any given scenario.

#### 1.4.1 Range and nature of literature

The ethics literature is extremely vast, and it is likely the searches do not cover the full range of written (or other) work in the area. This is not a problem exclusive to this thesis! Items missed in one element of the search, but that had relevance, tended to reoccur through other searches or in citations. I am confident that a significant number of relevant materials were selected to form the basis of the work. As well as drawing from the ethics and philosophy literature, the work is supported by contributions from sociology– it would be inappropriate for a discipline which deals with 'the messy situations that come up in real life' (Levitt 2004 p.82) to ignore them.

Some of the literature I use in articulating Paganism and its concepts does not meet the conventional standards of academia, although it does represent the views of (some) varyingly influential members of the Pagan community. Little is known of the extent to

180

which published Pagan literature influences self-identified pagan belief, although it is noted as having a market dimension (Rinallo, Maclaran et al. 2016). The full range of Pagan beliefs cannot be covered in the thesis and retain sufficient depth, so the cited sources are often those that represent overviews or have particular relevance to healthcare.

#### 1.4.2 Author as Pagan

200

210

I recognise that as a practicing Pagan, there may be a tendency to be biased in my interpretation in favour of one that supports Paganism. I openly begin from a standpoint that religion is something that should be accommodated when possible during healthcare interventions and recognise reflectively that this position is informed by my personal background. Similarly, my experiences as a medical educator, disabled person and woman with the privileges of education and whiteness inescapably inform my position.

My method is grounded in analytical and applied ethics, thus it is the quality of the arguments and inferences drawn from them that is the focus, and not a desire to promote any personally held belief system. However, my personal Paganism has driven me to evaluate ethical considerations in a way that might not arise for others, and I perceive this as a benefit for a discipline which should consider a broad variety of viewpoints and lived experiences.

# 1.5 Contextualising the Thesis: religious beliefs and healthcare

When people speak of 'Religion' they are often referring to the beliefs, practices and doctrines of the largest of the world's religions, and perhaps also more specifically those

religions more familiar in the 'West' (Guinn 2006 p.346) - Christianity, Islam, Judaism, Hinduism, Sikhism and Buddhism.

Christianity, Islam and Judaism share a common root, they are known together as the Abrahamic religions. Hinduism, Sikhism and Buddhism, however, are sometimes referred to as Eastern Religions because they arose in South East and East Asia. Some groups consider there to be nine world faith groups, once Zoroastrianism, Baha'i and Jainism are included (Department of Health 2003, Swift 2015). Additionally, there are numerous other faiths, such as Shinto or Taoism, numerous tribal and indigenous 'folk' religions, and syncretic religions, such as Santeria or Voodoo (Central Intelligence Agency 2015). Within each grouping of religions, there are numerous sub-groupings (denominations, and sects) meaning that despite having some common core beliefs, each subgroup will differ, often radically, in practice and doctrine. Christianity, for example, includes Catholicism, Orthodoxy and Protestantism, whereas Buddhism includes Theravada, Mahayana or Vajrayana (Smith 2009). Sociologists have noted changes in the roles and nature of religious organisations and the religiosity of religious followers (Aldridge 2013). The things we recognise as religion are in flux as the 'modern' cultural patterns of recent centuries give way to the 'postmodern'. The historically recent Paganisms of the thesis are interesting developments within this period of change.

Gaining recognition as a religion has advantages- gaining legal protections, tax benefits, legitimisation of beliefs rather than being a cult, and a level of respectability (Aldridge 2013 pp.13-16). Whereas numerous attempts have been made to define 'religion', finding something that is neither overly inclusive nor exclusive has proven a difficult, perhaps even futile thing (Guinn 2006 p.347). Numerous elements have been proposed, both philosophical and sociological, ranging from an approach to Ultimate Reality, the sacred or

230

the supernatural via ritual and symbolism to the functions of religion in meeting psychological needs (McKinnon 2002, Guinn 2006). Robertson (1970 p.47), for example, makes the distinction rest on 'a set of beliefs and symbols (and values directly therefrom) pertaining to a distinction between the empirical and a super-empirical, transcendent reality; the affairs of the empirical being subordinated...'. Sociologist Geertz (1973 p.90), however, refers to the system of symbols that produce motivations and facts of life, which does not require a transcendent to act as a religion in people's lives. The truth of what a religion is, when it is shaping healthcare interactions, contains a little of both of these, both the belief in the transcendent, and the meanings and behaviours that exist for the believer. McKinnon argues that we cannot define 'religion', as our inescapably ethnocentric definitions exclude, or do not adequately include, phenomena that we 'know' are religions (McKinnon 2002 p.67). For McKinnon, Wittgenstein's classification of games as a 'family of resemblances' (Wittgenstein 1953 trans. G.E.M. Lanscombe) provides a way of thinking about religion; solitaire and chess and football (and more recent than Wittgenstein, videogames for example) are all 'games' but very different from each other. Similarly, although Christianity, Buddhism and Hinduism are very different, they have a set of family resemblances which makes them all 'religions'. Ultimately, there is no rigid boundary to religion (McKinnon 2002 p.73).

As the thesis will later show, a strict definition of religion is not critical. I adopt instead a loose framework, that relates to the phenomena of religion that impact on healthcare in particular. It draws on many of the 'resemblances' and commonalities between different religions. I consider religion as a *framework of adherence to a combination of belief and behaviour that facilitates connection to a 'transcendent other' and fosters a sense of morality, meaning & purpose in its adherents*.

250

This means the kinds of beliefs that I am discussing in the thesis are those where the individual's conviction that there is a transcendent element to the world directly impacts on their way of being. For example, strong adherents to the familiar Judeo-Christian belief that God created the world and is interested in the behaviour of those He created, will follow His commandments on morality. Buddhism, as another example, lacks a deity but nevertheless acknowledges a transcendent something beyond conventional reality which impacts on human existence, thus is also a religion (Herbrechtsmeier 1993, Southwold 1978). Equally, other non-theist systems, such as Taoism or Shinto, also possess some concept of 'other' that makes them, at least, to an extent religious in nature. Some of the beliefs arising in connection with the existence of the transcendent are more relevant to healthcare than others. Beliefs about the beginnings and value of life, access to an afterlife, the acceptable use of animals and human modesty have direct impact on interactions with the healthcare system.

Religious beliefs still shape the behaviours of millions of the world's people, even though particularly in the West the influence, at least of mainstream religion seems to be in decline. What was once *the* authority on morality and life, has become not only side-lined but in some cases disdained, particularly by vocal secularists such as 'the New Atheists' (Kaufman 2019). The 'New Atheists' are predominantly rationalists who see religion as about fundamentalism and as granting unreasonable exemptions to public law. <sup>4</sup> They claim religion (all religion) is tyrannical, intrinsically hostile, and a gateway to extremism. And

270

<sup>&</sup>lt;sup>4</sup> Four authors in particular led the first charge, earning them the nickname the 'Four Horsemen'. Example works are *The God Delusion* (Dawkins 2007 p.306), *Breaking the Spell* (Dennett 2006 p.9), *God is not Great* (Hitchens 2007 p.280) and *The End of Faith* (Harris, Sam 2006 pp. 106, 225). I note that 'New Atheists' are also almost always well-educated white men, which may have some relevance, given discussions in chapters four and five.

whereas they have a point, in that people professing religion have done many atrocities and have harmed a great many men, women, children and LGBT folk directly and indirectly; those with religious beliefs have also saved lives, healed the sick and sheltered the homeless. The good does not undo the bad, but it is not wholly undone by it, either. The same might also be said for secular atrocities, such as Stalin's purges. For Kaufman (2019), the New Atheists have done little to advance the debate; they are too blanket in their accusations, too fundamentalist in and of themselves, too shrill in tone, too vitiriolic and too enthused by their scientific authority rather than developing good philosophy (Kaufman 2019). However, the rhetoric of New Atheism is persistent, and it may shape the way in which people think of others with beliefs; a rhetoric that described religious believers and religious beliefs as- 'lazy', 'fools', 'infantile', 'insane', 'toxic', 'brainwashed' and 'oppressive' (Kaufman 2019 pp.1-2). This is damaging language, encouraging the treatment of those who profess a religious belief as unworthy of our concern.

#### 1.5.1 Religious belief in healthcare

When a patient has a religious belief that affects their care, failing to adequately account for or accommodate it has the potential for suffering, both physical and psychological. Religious beliefs in patients can lead to a clash of moral frameworks in secular healthcare organisations. Religious beliefs can lead to patients refusing treatments and interventions, and there are also negative attitudes to people with religious beliefs. Religious individuals may also have moral misgivings about the existence of some kinds of human diversity within a pluralistic country.

The kinds of accommodation that might be requested are diverse. The literature frequently discusses refusal of best treatments such as blood products (e.g. Ridley 1999) and demands

310

290

for futile ones (e.g. Orr, Genesen 1997) but there may also be requests for such things as specific genders of health professional for reasons of modesty (Samra 2011), provision of food and medicine that does not violate religious strictures (Newson 2010), consideration of birth and death practices and disposal of body parts (Kirkup 2007, Sulmasy 2009) and access to worship, prayer and religious representatives (Swift 2015). There is also a recognition that accommodations can be supportive and promote patient wellbeing (Ravishankar, Bernstein 2014). However, research into the experience of chaplains and the needs of religious patients reveals that organisations like the NHS are failing to fulfil their own commitment to religious/spiritual care (Carey, Cohen 2009).

#### 1.5.2 UK healthcare provision

The bulk of healthcare in the UK is provided by the National Health Service (NHS). Since its inception, the NHS has striven to provide high quality healthcare to all, independent of means to pay. It is (mostly) free at point of contact for the people who use it – dental care is an exception. The costs of over £100bn per year (NHS Choices 2015a) are met by the taxpayer and managed on behalf of the Government as a public service. Unlike the United States and other Western countries, health insurance is not a requirement at any tier of society. Instead, universal healthcare for all is funded through taxation. Although in recent years there has been take-up of insurance – approximately 11% of the UK have some form of private health insurance – this has dropped again due to economic difficulties (Brindle 2010, King's Fund 2014 p.3).

One of the consequences of this state provision is that the NHS has the ability to systemwide manage its ethos. In 2009 the NHS Constitution was launched (NHS 2015), for the first time explicating the aims and goals of the entire organisation. The presence of the

320

constitution demonstrates, among other things, the NHS's commitment to the people it serves, a commitment not only for medical care, but for medical care delivered compassionately and without judgement on a patient's beliefs or status. As an organisation, the NHS seeks to discriminate only on the basis of medical need.

The NHS serves a multicultural population within an ostensibly secular state. Among its patients and staff are those from numerous ethnic, cultural and religious backgrounds with the accompanying moral conflicts such differing backgrounds create. The NHS is constantly in flux for this, and other reasons. The costs of providing care and the costs of administering the numerous hospitals, practices and other centres of care have escalated alongside a growing (and aging) population that increases demand. New, expensive, treatments prolong and improve life to an extent not envisaged when the NHS was founded. Some fear that an increasingly marketised and privatised system will be the solution to spiralling costs<sup>5</sup> (Frith 2013). Discussions about how treatments may be ethically rationed are common in the literature (Cappelen, Norheim 2006, Rosenblatt, Harwitz 1999, Newdick 2005, Brauer 2009, Maxwell 2009). Recent scandals such as that at Mid Staffs Hospital (Francis 2013) -to which I have a familial connection- have highlighted failures of care caused by obsessive target meeting and mismanagement of both finances and people, prompting and supporting the case for reform. Government involvement in the NHS is a topic of contemporary concern, with politicians of all allegiances aware of the electoral and economic 'hot-potato' the NHS represents, with current debates around the ability to close hospitals, information

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management and reforms to the way primary care is commissioned.

<sup>&</sup>lt;sup>5</sup> Interestingly, however, per capita and %GDP health spending can be greater in countries where there is private health insurance (Office for National Statistics 2016).

#### 1.5.3 The NHS Constitution

[The NHS] is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most (NHS 2015 p.2).

If this is the stated purpose of the organisation, it could reasonably be inferred that there is an obligation imposed on the NHS to fulfil this purpose; taking adequate account of not only the saving of lives but the provision of care and compassion. Several of the principles clearly apply to caring for religious patients.

Principle one of the constitution states that '[t]he NHS provides a comprehensive service, available to all' (NHS 2015 p.3), specifically mentions a duty to patients regardless of religion, and that it must 'must respect their human rights' – of which freedom of religion is one.

Principle three, about excellence and professionalism, requires patients and staff to be treated with 'Respect, dignity, compassion and care' (NHS 2015 p.3). Respect (and compassion), as I will argue in later chapters, necessitates a consideration of religious beliefs.

Principle four states that '[t]he patient will be at the heart of everything the NHS does' and that 'NHS services must reflect the needs and preferences of patients, their families and their carers' (NHS 2015 p.3). The prioritization of the patient echoes the professional guidance that places the patient first. This suggests that NHS services should be suited to a whole

360

variety of needs, not only those dictated by medical necessity. Religious needs can (and as I will show later, should) fit easily within this remit.

Principle six commits the NHS to 'providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources' (NHS 2015 p.4). A limiting factor on the extent to which religious beliefs should be respected will therefore be the affordability of any accommodation of those beliefs, and the principles on which the budget is shared between patients.

The constitution also makes *pledges* to patients which include 'the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, **religion**, **belief**, gender reassignment, pregnancy and maternity or marital or civil partnership status' (NHS 2015 p.6). The document also lays out pledges to and the duties of staff, including the provision of training and the duty of compassionate and respectful treatment to patients (NHS 2015 pp.12-14). The particular relevance of training needs is that where there is ignorance about religious matters that impedes the performance of staff duties, the NHS may need to facilitate the provision thereof, and staff should seek it.

#### 1.5.4 NHS Guidance on Religion and belief

Specific guidance on Religious belief is available in the form of centrally produced NHS documents, such as the *Guidance on Religion or Belief* (Department of Health 2009). Individual trusts also produce handbooks and guidance for their staff.

The guidance document on Religion or Belief makes it clear that the NHS recognises that: spirituality (religious or not) is an important aspect of a person's life, that religious and cultural views can influence attitudes towards numerous elements of medical care and

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should be accommodated wherever possible, that the beliefs of staff should not adversely affect their relationships with colleagues and patients, that the NHS will not seek to make staff violate their own religious beliefs wherever possible, and that unwarranted discrimination on the grounds of any belief or none is not acceptable (Department of Health 2009).

#### 1.5.5 Existing ethical approaches

Numerous approaches have previously been taken to exploring and justifying responses to religiously based requests for accommodation. In the thesis I look at Beauchamp and Childress' (2012) ubiquitous four principles, with particular reference to respect for autonomy and to beneficence; the question of tolerance and religious freedom, alongside related UK equality legislation; and the use of ethical 'weighting systems' such as proposed by Buryska (2001) and Bock (2008).

A key contribution from Beauchamp and Childress' work is the use of respect for autonomy', and in particular its impact on determining under what criteria a patient is able to give or refuse consent for a procedure, and the use of an 'informed consent' model. Autonomy has a long history in ethics and political theory; respect for autonomy, however, can be narrowly interpreted. Some feminist ethicists (Sherwin 1989, Held 2006, Stoljar 2000) argue that it is a limited way of responding to others; part of a systemic devaluing of obligations to care.

Others among the principles also have long histories – such as non-maleficence and beneficence. Beneficence is a demanding principle, as it imposes an obligation to actually assist, and is limitedly applied compared to respect for autonomy in public sphere ethics. It is, however, considered an essential value within medicine, and for commentators such as Thomasma and Pellegrino (1988), the primary one. Whereas informed refusals sit uneasily

410

between respect for autonomy and beneficence, requests for accommodation that don't involve a refusal are ill supported by standard autonomy claims and are best supported via some conception of beneficence. However, some of these requests take resources away from others, requiring further balancing of principles such as a commitment to justice through fair allocation, and the risk of harm to others. Where requests are driven by religious motivations, Orr and Genesen (1997) argue that the balance may fall in favour of the religious request, whereas Savulescu (1998b) considers this unreasonable.

Important legal and socio-political factors also have an impact on how religious requests are accommodated. Health professionals work within convoluted legal frameworks and networks of rights and duties, such as the Human Rights Act 1998, professional guidance and Equality Legislation (e.g. *The Equality Act 2010*), plus accompanying case law which shapes and/or clarifies key portions of legislation. Power disparities and vulnerabilities in the patient population can be exacerbated by membership of a group such as a religious one, such as the contemporary vilification of Muslims because of acts of terror committed by some in the name of Islam, the influence of religious conservatives on limiting abortion provision, and a ban on Female Genital Mutilation. Mediated by tolerance, a balance needs to be struck between supporting, allowing or preventing people's religious expression, given that media narratives around religion are frequently divisive (Butler-Sloss 2015).

The process of balancing rests on the idea that reasons give weight to prioritising one principle over another in particular instances (Beauchamp, Childress 2012 pp.20-24). Given that according to Wreen (1991) and Orr and Genesen (1997) religious beliefs deserved consideration in healthcare decisions, Buryska (2001) proposed some 'principles for determining when claims based on religious beliefs or cultural sensibilities "trump" other considerations and when they do not'. Bock (2008) also sought to encapsulate the balancing

430

process within a set of criteria in which the nature of the belief, risk of harm, and balance of burdens were weighed relative to each other alongside other ethical considerations. In some cases, the request for accommodation beyond the normal will gain sufficient ethical weight to be met.

#### 1.5.6 Paganism

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The modern manifestations of Paganism were founded long after the 'disenchantment' of the secularized world had begun, making Paganism particularly interesting to sociologists. However, Pagans are frequently misunderstood and misrepresented (Harvey 2011, Tejeda 2014). Much comes from the impact of media portrayal, which tends to generally sensationalise negatives and/or present unusual lives and beliefs as weird and shocking. Pagans are a target for popular portrayals of 'witches' as old green women with warts, or seen as 'satanists and devil worshippers', although more positive representations have appeared over the last 15-20 years.

There are a number of distinct Pagan paths (Wiccans, Druids, Heathens) as well as eclectic Pagans (who do not consider themselves part of one path specifically), which prompts Harvey (2011) to refer to them collectively as Paganisms. Paganism lacks a central dogma, largely consists of people who have chosen rather than been born to the religion, and often encourages personal relationships with the divine. Paganism therefore lacks the type of the large, authoritarian, traditional communities associated with 'religion', and thereby

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<sup>&</sup>lt;sup>6</sup> Max Weber borrowed the expression from Friedrich Schiller (Aldridge 2013 pp.41-42).

<sup>&</sup>lt;sup>7</sup> What the public like to call Satanism, and what Satanism actually is, are also widely different.

immediately challenges assumptions about what religion means, and whether weighting systems devised with Abrahamic faiths in mind can adequately respond to Pagan beliefs.

Paganism is also an interesting context because the number of Pagans is apparently growing faster than the population (Office for National Statistics 2012, Office for National Statistics 2013, Pitzl-Waters 2013), although still a minority by comparison to the largest faiths in the UK and when compared to 'no religion'.

#### 1.6 Thesis Structure

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#### 1.6.1 Chapter one: Introduction

An initial exploration of the key context, themes and structure of the thesis, setting the scene for the work.

#### 1.6.2 Chapter two: An introduction to religions and Paganisms

I begin the chapter with a consideration of world and UK religious belief. I identify common features generally associated with religion to provide a comparison with Paganism later in the chapter. With reference to Smart (1995) and Benjamin (1990), I consider the nature of religious beliefs and their relationship to worldviews and identity, which shape the appropriateness of ethical accommodation. I highlight the changing nature of religion in light of concepts such as modernity and postmodernity (Giddens 1991 p.15, Goodin, Bennett 2013) and evidence from the US based NSYR (Smith 2009). I then illustrate the key tenets of Paganism, demonstrating that Paganism fits both within the definition of religion and exhibits modern and postmodern features; beliefs that arise from Paganism are as much religious beliefs as those of the more well-known religions, meaning they deserve consideration as such. The diverse and changing nature of religious adherence means that

considering ethical bases of accommodation that work for a variety of beliefs is an important exercise.

#### 1.6.3 Chapter three: The impacts of religious belief in healthcare

The second chapter considers how religion in general can have impacts on healthcare. I use the literature to illustrate the impact of religious beliefs on treatment decisions and how this raises issues of ethical concern. I then construct three example cases where Pagan beliefs cause conflict within healthcare. The ethically salient points of the cases (respect for autonomy and capacity, beneficence and harm, staff understanding and attitudes, plus resource allocation) give rise to the considerations in chapters five and six. The overall purpose of these scenarios is to illustrate an evaluation of ethical ways of accommodating religious beliefs in chapters seven and (particularly) eight.

#### 1.6.4 Chapter four: Care respect for persons

The first section deals with accounts of personhood and respect given the significance granted to the concept of 'respecting' the beliefs of religious persons. I consider the limitations of considering persons to be mere representatives of certain valued concepts such as reasoning and autonomy, recognising that the interconnectedness and emotional nature of people has more value than is traditionally given in discussions of personhood and autonomy. I thus introduce the concept of care respect (CR) to bridge a gap between a person-centred ethics of care and respect for persons, making respect *particular* and orientated around the concept that we owe obligations to others because of a recognition respect for their intrinsic qualities.

510

The second, smaller, section justifies accounting for and accommodating religious beliefs on the basis of CR. Respect is not owed to the religion per se, but to the fundamental part of the person it represents. I note that an additional element of religious belief is keeping to moral obligations, a form of integrity that we are inclined to respect in day-to-day life.

#### 1.6.5 Chapter five: Autonomy, beneficence and care respect

Having established we have reasons to respect religious beliefs and situations in which they impact on health care, this chapter explores current approaches taken to accommodating religion and belief. Two particular reasons for accommodation are explored, respect for autonomy and beneficence.

In the first section I explore the nature of liberty and agency as parts of accounts of autonomy. I use respect for autonomy as presented by Beauchamp and Childress as relevant to healthcare, exploring concerns about rationality and capacity (Savulescu and Momeyer 1998, Hyslop 2017), voluntariness and authenticity (e.g. Hyun 2002), as well as concerns from feminist ethics (Code 1987, Donchin 2000). I argue against an approach to the value of religious beliefs in decision making which requires a highly critical analysis of truth claims, supporting instead accepting a patient's voluntary, religiously based decision provided they understand broadly the nature of the medical condition and potential outcomes. This represents a *sufficient understanding of the facts* (because these are the facts that necessitate the decision itself) as well as the ability to decide in light of one's own values required for a valid consent or refusal.8

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<sup>8</sup> It would perhaps also be appropriate to look (in future) at other factually-relevant issues – such as the availability of benefits and social support, within medical decision making.

The care respect approach calls for care, cherishing, and support in terms of flourishing and this is not the natural strength of a respect for autonomy approach. In the next section I explore the concept of beneficence, generally seen as in imperfect duty in healthcare and often focuses on the biomedical good. Religious beliefs, and the accommodation of those beliefs, have a benefit to patients which goes beyond the biomedical, and may even be in opposition to it. I note that sometimes religious beliefs can be unhelpful, in which case accommodating them might not be justified. However, I argue that when accommodating religious beliefs is beneficial to the patient, then we are justified in making those accommodations under a beneficence principle and from care-respect.

## 1.6.6 Chapter six: Limitations on the accommodation of religious belief

Religious belief does not mean 'anything goes'. There are legitimate limitations that can and should be placed on accommodation of religion in healthcare. Primarily these are insufficient understanding of the medical facts, imposition of harm upon another person who is unable to decide for themselves, legitimate concerns about respect for people within a liberal democracy, and the unavailability of the requested intervention.

In the first section I discuss limitations imposed by respect for autonomy in terms of decision-making ability. I re-emphasise that it remains essential for the patient to understand, but only in general terms, that they are ill and that this (and any proposed treatment) will have effects on their life and re-state that decisions should be the patient's own. With reference to adults who lack capacity, and the care of children, I use autonomy, in the sense of bodily authority, to limit decisions made about the care of a patient based on religious beliefs, to those decisions made about the patient by the patient themselves.

Even if we seek to be tolerant (which we ought to do under CR) we have grounds for limiting accommodation. These limits include:

Harms; particularly those coming to others than the patient. Harms include physical, emotional and psychological hurt, and loss of dignity.

Legislation: such as human rights and equalities legislation, and the accompanying case law. The Human Rights Act (1998) and The Equality Act (2010) illustrate the key legal priorities in accommodating religious beliefs. Case law, including Case of Eweida and Others V the United Kingdom (2013), illustrate there is a necessary balance between the freedom to practice religion, and the upholding of other human rights.

Possibility; we are not ethically obligated to do what is impossible, whether this is through resource limitations or the limits of medicine. I discuss three examples of such limitations – medication availability, chaplaincy and futility.

# 1.6.7 Chapter seven: Balancing conflicting obligations; weighting system approaches

In the first section I lay out the obligations that derive from CR, as argued in chapter four, five and six. The obligations require further application in individual cases, and I go on to consider the use of a weighting system.

I systematically evaluate the criteria presented by two such systems, (Buryska 2001, Bock 2008). These systems and lack attention to the beneficent and person-oriented requirements of a care-respect approach, and over-play the importance of large, traditional communities as sources of weight. Whereas the presence of a community might be a shorthand for having epistemic resources devoted to the formulation of beliefs, as Bock claims, for Pagans, finding such a community or even recognising that it exists is difficult.

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## 1.6.8 Chapter eight: A care respect approach to accommodating the religious beliefs of modern Pagans

In this chapter I propose a new 5 criteria weighting methodology that is derived from a CR position. I illustrate, with reference to the three hypothetical cases used in my introduction, that when a request or proposal for accommodation meets the criteria, it has a very strong weight and should, most often be met.

In the second section of this chapter, I also highlight three potential areas for staff development, given that research shows inadequate skills among HCPs at dealing with religious and spiritual matters in healthcare. I identify a need for training, the benefits of taking a spiritual history, and the potential value of 'religious interpreters', which would help improve the understanding of, and accommodation of, religious beliefs in healthcare.

#### 1.6.9 Chapter nine: Conclusions

Paganism should be accorded the same respect as other religions in the NHS as it fits sufficiently within the family of religions to do so.

CR requires a demanding but inclusive approach to accommodation of religious belief. Because religious beliefs are central to identity, a particular approach to persons such as the one advocated in CR, supports accommodation on the grounds that to do otherwise would be to fail to respect that person. This accommodation does not permit everything, and therefore there are reasonable grounds for not acceding to all religiously motivated requests which can also be derivable from CR.

CR thus produces principles which support and principles that limit accommodation. Weighting systems can be used to apply the obligations of CR to distinct cases.

The most basic way of showing respect is in daily interaction, in caring about others, which need not be expensive or resource consuming. Training in the use of weighting systems and in different beliefs should be encouraged.

Potential areas for further research are formal documentation of Pagan beliefs around healthcare and their experiences within it, application of CR to other questions in healthcare, and the extension of the weighting systems to healthcare professionals.

# 2. An introduction to religions and Paganisms

The purpose of this chapter is to clarify the nature and importance of religious beliefs to those who hold them (providing important grounds on which to base accommodation), and to introduce the key features of Paganism (informing the example cases in the next chapter) which may be unfamiliar. This includes a brief exploration of the context of religious change and religious identity in the 21<sup>st</sup> Century.

Although there is great diversity in religion, there are some key themes in the family of religions. As I discussed in the introduction (section 1.5), defining religion is extraordinarily difficult. Instead, a group of 'family' commonalities can be considered which can be detected in many religious beliefs (McKinnon 2002). Significant among those is the presence of the transcendent (section 2.1.1), something which is apart from mundane and material existence. The presence of the transcendent, leads to beliefs and behaviours (2.1.2) which can strongly impact on the believer's way of life. These beliefs and behaviours may involve ritual, iconography, forms of worship, as well as morality (2.1.3) and other community action, which connect the believer to the transcendent and to others.

This chapter introduces the concept of the worldview (Benjamin 1990, Smart 1995, Sire 2004, DeWitt 2010). Worldviews are a way of comparing answers to life's fundamental questions, both religious and secular. The importance of a worldview in shaping way-of-life is ultimately crucial grounds on which to accommodate religious beliefs in healthcare.

In the second part of the chapter, I illustrate the key practices and beliefs of Pagans and also some of the damaging attitudes and responses Pagans experience from others. The beliefs of Paganism share the features of a religion and therefore Pagan beliefs are religious beliefs.

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On this basis, Pagan patients, therefore, ought to be given the same opportunity to have their beliefs accommodated in healthcare.

## 2.1 Religion in general

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As outlined in the introduction, religion takes many forms, varying between cultures and over time. Although a complete definition is impossible, family resemblances between the activities we call religion can be identified. The three of particular concern to the thesis are 1. the source of religious belief (a connection to the transcendent), 2. the behaviours linked to the religion and the transcendent, and 3. the moral and social obligations the religion generates for believers. Each of these will shape the way in which a religious person might interact with healthcare (discussed in chapter three).

## 2.1.1 Connection to the transcendent9

A key part of religion is an acceptance, as real or probably real, something which is not immediately, if at all, objectively verifiable from the outside. This non-verifiable reality is considered in some way 'transcendent' as opposed to immanent or material, for example, an *Otherworld* (Smith 2006 (2001) p.216, Greenwood 2000). Religion's important purpose is to connect to this transcendent reality, to allow people to ultimately *experience* something that cannot be adequately explained in words or out of context.

<sup>&</sup>lt;sup>9</sup> Information in 2.1.1 and 2.1.2 has, (except where otherwise referenced) been synthesised from the following references (Hinnells 1995b, Bowker 2000, Barker 2005, Hussain, El-Alami 2005, Nesbitt 2005, Cohn-Sherbok 2006, Warrier 2006, Dawson, L. 2007, Smith 2009, Dawson, John B. 2011b, Sikhs.org 2011, Samra 2011)

This transcendent other takes many forms and each religion has a different relationship with it. In Trinitarian Christianity -God the Father, Son and Holy Ghost. In the other Abrahamic religions, Allah or Yahweh. In Buddhism, the transcendent reality is *Nirvana*, in Hinduism there are numerous deities that are devotional routes to personal release from the cycle of rebirth. It could be the *Awen* of the Druids (Harvey 2011), or the *kami* of Shinto. Religion does not require a specific conception of transcendence, such as there being a single male God.

## 2.1.2 Religious behaviours

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However, mere belief in a *Transcendent* does not constitute religion; many people believe there is 'something out there' but this does not particularly affect their day-to-day behaviour in any way, as is the case with many of Bullivant's 'nones' <sup>10</sup> (2017). It is in combination with behaviours we see the pattern of religion emerge. Behaviours include but are not limited to ritual behaviours such as prayer or ceremony, the wearing of particular clothing and the use of particular icons. The behaviours are what we see, are affected by and interact with on a daily basis, it is therefore largely these behaviours which we initially seek to accommodate. Rituals of the well-known religions might include recitation of the Lord's Prayer in Christianity or chanting of Buddhist mantras, the *Sapta-Padi* of Hindu marriage, the burial of Muslims facing Mecca, *Amrit* for initiation into Sikhism, and the *Bat Mitzvah* of Judaism. Rituals need not be defined only as large public ceremonies or recitations of creed, but may also be personal and personalized prayers, lighting a candle to invoke spirit, a nod to the ancestors, or meditative silence to approach the transcendent. Religious symbols include

<sup>&</sup>lt;sup>10</sup> A term referring to people who expressed that they had no religion.

the *crucifix* of Christianity, the *Kara* of Sikhism, the hand gestures of Buddhism. These symbols also include the use of icons, such as Hindu statues of Shiva or the Jewish *menorah*. The symbols used represent key concepts or events beyond their existence as shapes or objects, representing a bundle of complex narratives and understandings (Hinnells 1995a).

However, many other groups that one can be a member of have requirements on behaviour, such as wearing a uniform, observing particular holidays, or performing certain actions. An actor may display the outward signs of following a religion for a role but does not follow the religion. Someone may attend services or pray from habit, to maintain relationships, or remain celibate for non-religious reasons. Although religions have behaviours, no behaviours are religions in themselves.

Non-religious ritual might include the awarding of Olympic medals, the donning of the graduation gown, giving birthday presents, or the chanting of a football song. Non-religious symbols also occur, such as the arrangement of gold, silver and bronze medals, or the use of a wedding band. Some manner of behaviour is therefore a necessary but not sufficient condition for something to be considered a religion. It is the behaviours' associations with the transcendent which makes religion, but this still lacks an important element. One could do all of the above without any moral obligations.

## 2.1.3 Morality, meaning and purpose

*People* and the *treatment* of other people are fundamentally at the heart of religion (and ethics). A religious belief attempts to *foster a sense of morality, meaning or purpose*, that is, to develop in its followers a sense of their place in the universe, their obligations to the divine and to other features of the world. There are many different meanings or purposes that can be suggested for human life – ranging from nothing (other than those which are

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are self-chosen) to objectives and meaning being determined by a greater, external, force. These purposes and meanings can drive human action. Religion also shapes attitudes to other aspects of daily life that are seen as having a moral component, for example religious young adults tended to have a greater sense of purpose, tended to feel less helpless, be more educated and less consumerist, cared more for the poor and elderly, engaged more in charitable volunteering, and engaged less with drugs and sexual activity (Smith, Snell 2009)

pp. 257-278). Religion, therefore, seems to have a clear relationship with not just symbolic

and ritual behaviours, but moral ones."

Many religions, such as Christianity or Islam, impose specific moral obligations in connection with the transcendent and beliefs about what is good. Others, like Buddhism or Quakerism may not, suggesting instead a more flexible pervasive ethic of compassion or non-harm. Either way, the moral imperatives are informed by the transcendent; even a belief as simple as "God wants people to be kind to others" (Smith, Denton 2009 p.162) represents a moral commitment, albeit not a very non-specific one. If the transcendent is a transcendental *being*, they may be considered to have made known their instructions on what good behaviour is through a codified doctrine, or through the words of those who are particularly enlightened. Alternatively, the existence of the transcendent motivates particular behaviours such as embodiment, appeasement, propitiation or respect for human potential which defines, or is part of good. As an example, the Ten Commandments are probably the most well-known set of religious moral rules in the UK, which can be identified as containing some very general rules (such as not to kill) and some particular ones (having

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<sup>&</sup>quot;Sexual behaviour, drug taking, work ethic and charity are recognised as areas of moral relevance. The behaviours shown in the study correspond to 'traditional' religious values in these areas, and should be seen evidence that people will live by a particular set of values, rather than as supporting that the moral value is appropriate.

only one God). Numerous other moral rules arise from religious beliefs, such as giving to charity - *Zakat* in Islam, *Das Vand* in Sikhism – and numerous other rules about the parity of genders, acceptable sexual behaviour, acceptable food and clothing and living with compassion. Individual followers may adopt and follow rules to varying degrees, but those rules for living, with attendant right and wrong, are shaped by the presence of some form of transcendent.

# 2.1.4 World and UK religious populations

It is difficult to get an exact figure for the number of religious believers around the world – difficulty in obtaining full counts from diverse populations and countries mean that figures are only estimates. Globally, Christianity predominates with around 33 million adherents (see table 1 below). Likewise, the figures which are reported in census figures and similar counts are only a snapshot, may differ in method between surveys, and say very little about how active someone is within their religious identity. However, overall adherence appears to be declining.

In the early 20<sup>th</sup> Century, sociologists Emile Durkheim and Max Weber predicted, and lamented the dull, disenchanted and bureaucratic world that was going to result from, the inevitable decline of religion (Aldridge 2013 pp.41-42). Contemporary sociologists recognise the changes (Aldridge 2013); in the UK, and many other Western societies, there has been a notable decline in religious adherence in the last century. The reason for the decline in religious adherence is variously attributed to post-modernity, increasing secularisation and the loss of the relevance of religion to people's lives (Crockett, Voas 2006, Dawson, A 2011, Aldridge 2013), although an account of the processes and factors is well beyond the thesis' scope.

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In England and Wales, the census of 2011 records around 60% of the population as Christian of one form or another (see table 2, below). NatCen's British Social Attitudes (BSA) survey has asked about religion with a small sample population over a number of years (see table 3, below). According to the BSA, the percentage identifying as 'no religion' has been steadily increasing, with over 50% of the sample population now reporting 'no religion'. Among people in the 18-24 age group, this figure reaches 71% (Harding 2017). However, Bullivant (2017 p.16) notes that among those reporting no religion in the BSA and its European counterpart, many still pray or consider themselves religious in some way. Whether these individuals care enough to practice in a way that meaningfully impacts their lives may be unlikely '[i]t is not enough to find that people accept one statement of belief or another; unless these beliefs make a substantial difference in their lives, religion may consist of little more than opinions to be gathered by pollsters' (Voas, Crockett 2005 p.14). Nevertheless, many people still do care about their religion in such a way as it impacts on their daily life and their medical treatment (see chapter three), and some sociologists consider religion and faith to be taking on new forms (Aldridge 2013 particularly chapter 8 and see section 2.1.10 below).

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## **Tables**

TABLE 1 WORLD RELIGIOUS ADHERENCE

Global Religion	% Estimate (whole figures where possible)	Notes		
Christian	32 -33			
Muslim	22-23			
Hindu	13-15			
Buddhist	6-7			
Sikh	0.35			
Jewish	0.2			
Other religions	7-11	Pewforum figures include Sikhism here, Factbook lists Baha'i separately)		
Non-religious/atheist	11.67			
(Central Intelligence Agency 2015, Pew Research Center 2012)				

TABLE 2 RELIGIOUS FOLLOWING ENGLAND AND WALES 2011 (OFFICE FOR NATIONAL STATISTICS 2012)

Religious following England and Wales 2011	Pop. Total 56,075,912	%	Comments
Christian		60	Protestants including the Church of England Methodist & Jehovah's Witnesses reported their specific faith in the highest numbers. Roman
	33,243,175		Catholics also feature strongly.
Buddhist	247,743	0.4	
Hindu	816,633	1.5	
Jewish	263,346	0.5	
Muslim	2,706,066	4	
Sikh	423,158	0.8	
Other religion	240,530	0.4	
No religion	14,097,229	25	

## TABLE 3 BSA RELIGIOUS AFFILIATION IN THE UK 1983 – 2016 (NATCEN 2017)

Sample UK population	1983 (1,761 adults)	2000 (3,426 adults)	2016 (2,939 adults)
identifying religious			
affiliation			
Christian	67%	55%	41%
Non-Christian	2%	5%	6%
No Religion	31%	40%	53%

## 2.1.5 Distinguishing spirituality and religion

The literature often draws a distinction between 'spirituality' and 'religion', with spirituality being an interest in the intangible part of oneself and a search for meaning and 'divine' connection, rather than following the prescriptions and forms of a particular belief (Berlinger 2004, Barber 2012, Dyson, Cobb et al. 1997, Aldridge 2013 pp.186-191). At the widest separation between the two it is not difficult to see a distinction between them – a fundamentalist who follows a literal interpretation of their holy book and the humanist who nurtures a sense of personal enlightenment through wonder at the natural world. Although both have an interest in an intangible element of themselves, the literalist is clearly 'religious' and the humanist plausibly 'spiritual'. Between them we may find a Sufi mystic, or an agnostic who uses tarot as a reflective methodology, or the person who believes there is 'something' but rejects the notion of 'organised' religion, or the lapsed Catholic who nevertheless attends mass out of a sense of belonging. Personal engagement with the transcendent can be mediated by religion, but it need not be.

The clearest difference seems to be in structure; religious groups and movements often have some form of institutional dynamic – that is, various structures, hierarchies and administrative procedures that enable the religion to function– even those that eschew obsessively formal approaches. The institution reflects the ideals of the organisation, providing doctrines, leaders, rituals and spaces, but also the practical necessity of communications, mobilisation, finances and the like (Dawson, A 2011 pp.29-30). The person who is 'spiritual but not religious' (Dawson, A 2011 p.88) may lack this institutional dimension and/or other elements of morality and purpose but equally may not. Those who have found difficulties in the hierarchical and dogmatic structures of organised religions – institutions are subject to human weaknesses, after all- sometimes reinforce the idea they

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are not abandoning belief in or sensitivity to intangible things, but instead have abandoned the idea of religion. 12 Other authors (Smith, Snell 2009 pp.296-296) suggest that 'spirituality' and being 'spiritual but not religious' are both ill defined, and not as common as may be supposed.

As this thesis progresses, a distinction between religion and spirituality need not always be clearly drawn in terms of giving ethical weight to beliefs. It does not matter if it is a religious belief held by one or a million, although there are practical advantages from being part of a million. The number and organization of believers matters much less than the fact they believe and the way in which their beliefs shape their identity and behaviour, so outside of the unfortunate arena of collective bargaining, the 'religion' tag becomes much less important. I will retain something of a distinction, however, because it is one both believers and non-believers themselves find useful, and because it keeps this thesis more closely aligned to the religion concept.

## 2.1.6 Religious beliefs and worldviews

Although all religions differ from one another, and within themselves (depending on the regional and temporal origins of particular groups), some repeating ideas emerge. Religious Studies scholar Ninian Smart (1995) expresses that the categories under which religious beliefs (and indeed, all worldviews) can be understood as comprising six dimensions, the experiential, doctrinal, ethical, mythic, ritual and social (pp. 6-9).

(Dawson, Andrew 2011 chapter 8)

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<sup>&</sup>lt;sup>12</sup> Some commentators consider this itself to be symptomatic of a commercialisation of belief

The *experiential* (or *emotional*) *dimension* is feeling the presence of the divine; an emotional response to the transcendent, perhaps producing *numinous* feelings of awe, solemnity, reverence or exultation in the presence of a higher being. In *mysticism* the transcendent and the self, become one and the same.

The *doctrinal* (or *philosophical*) dimension consists of beliefs about how reality is, and the *ethical* (or *legal*) *dimension* consists of beliefs about how to be, what is right and wrong and what humans ought to strive to become.

The *mythic* (or narrative) dimension, includes the histories, stories and legends which act as powerful metaphors to explain and reinforce the other elements. For example, the story of Genesis in the bible is an origin for human beings, the theory of evolution is another narrative of human origin. Symbols that evoke and represent key concepts and narratives may help to connect believers with this reality and with doctrine.

The *ritual* (or *practical*) *dimension* facilitates this connection, allowing believers to interact with reality (or scientists to conduct experiments).

Finally, within the *social* (or *institutional*), people mark rites of passage, and other communal celebrations or gatherings to shape connections within the community (and with the divine). The social dimension also covers structures of power and influence over and within society.

What Smart is expressing here -and indeed it gives the title of his book (Smart 1995)- is a way of exploring what are known as *worldviews*.

#### 2.1.7 Worldview

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'a set of fundamental beliefs, values, etc., determining or constituting a comprehensive outlook on the world; a perspective on life'

(Oxford English Dictionary Online Edition, no date)

A worldview relates to how an individual conceptualises their relationship to the world in which they live. A worldview represents, to the holder of the worldview, reality. These worldviews may be secular or religious; they may be influenced by political ideologies or religious traditions, and they are built through socialisation, education, personal experience and vicarious learning. Worldviews are often built unconsciously and arise from the opportunities and experiences of the particular individual; it remains important to recognise that although some worldviews are unusual, or not mainstream, the value the worldview has for the individual is independent of the value ascribed to the worldview by others.

Understanding the elements of a worldview enables me to illustrate that religions (and other ways of thinking about the world), in my example modern Paganism, address the key questions of human existence. By showing how important worldviews are, I can illustrate that they are a potent element of justifying respect for religious beliefs and Pagan beliefs in particular.

Martin Benjamin describes a worldview as;

[...] a complex, often unarticulated (and perhaps not fully articulable) set of deeply held and highly cherished beliefs about the nature and organisation of the universe and one's place in it. Normative as well as descriptive – comprising interlocking general beliefs about knowledge and values – a worldview so conditions our thinking that it goes largely unnoticed (Benjamin 1990 p.88).

James Sire (2004) states;

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a worldview is a commitment, a fundamental orientation of the heart,<sup>13</sup> that can be expressed as a story or in a set of presuppositions (assumptions that may be true, partially true or entirely false) which we hold (consciously or subconsciously, consistently or inconsistently) about the basic constitution of reality, and that provides the foundation on which we live and move and have our being (Sire 2004 p.125).

Worldviews seek to answer key and fundamental questions which should not be unfamiliar to most people. There are multiple potential lists of the questions available, and a definitive one is unlikely, particularly as Sire notes (2004 p.121) that the concept of worldview is itself worldview dependent. The following seven fundamental questions that would be answered by a worldview are built from Benjamin (1990 p.88), Sire (2004 p.20) and permeated throughout by the six dimensions (Smart 1995 pp.7-8). Each big question asks many smaller questions, leading to an extensive number of potential worldviews. The worldview in turn shapes 'ways of life'. That is 'coherent totalities of customs, attitudes, beliefs, institutions, which are interconnected and mutually dependent in patterns that are sometimes evident and sometimes subtle and concealed' (Hampshire 1983 p.6).

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<sup>&</sup>lt;sup>13</sup> Heart here does not refer to a more conventional reading of heart as an emotional reference, but as one that includes a deep wisdom or *knowing* that is not necessarily created from intellectual inquiry. One 'feels' a worldview as much as, if not more than, being able to logically express or order it.

## 2.1.8 Questions of the worldview

- What is prime reality the really real? For example, is this God or Gods, or a material reality only? <sup>14</sup>
- What is the nature and purpose of the world around us? <sup>15</sup> Was it created? Do we have a personal or objective relationship with it? Does the world have a purpose such as preparing us for heaven or is it purposeless? Is it material, spiritual or a combination?
  - What are human beings?<sup>16</sup> Do we have souls or some form of persisting consciousness?

    Are we purely biological machines, or do we contain sparks of divinity? Do humans have a purpose?
  - What happens when we die? <sup>17</sup>
  - What can be known by humans, and how? What can we know? How can we be sure of our knowledge? What constitutes truth?
- What is (the right) morality? Is morality an aspiration or a duty? Are the rules flexible
   or inflexible and from where do they stem? What can and can't we do in terms of our
   moral obligations to others, both human and non-human?<sup>18</sup>

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<sup>14</sup> Benjamin asks this question as being about God – thus is there a God, or not. I prefer the more positive framing of it by Sire which does not define it (potentially) by the absence of something.

<sup>15</sup> Benjamin's option 2 is about the purpose of nature and human beings.

<sup>16</sup> Benjamin's option 3 is about knowledge, which is Sire's 5th option.

<sup>17</sup> Missing from Benjamin's options, but I consider it fundamental enough to be included, as Sire does, as question 4.

<sup>&</sup>lt;sup>18</sup> Benjamin has a separate section for the morality on non-human things such as animals and the environment.

• What is the best way to live life? What kind of family structures, social roles and aspirations are appropriate? What is acceptable in terms of sexual, political, family and friend relationships?<sup>19</sup>

As examples of the ways in which secular versus religious worldviews diverge, the atheist scientist may answer questions about the existence of God or other transcendent in the negative (philosophical), think of humans as the result of evolution (narrative) and will discount ideas of sins staining an immortal soul and perhaps embrace utilitarianism (ethical). The devout Catholic may answer the first question with a God (doctrinal), consider humans to have originated in Eden (mythic) and morality to be determined (in part) by the edicts of the Pope (ethical), whereas a Protestant, answering questions about God in a similar way, may resolve latter questions differently. Someone may interpret the vast beds of Silurian<sup>20</sup> rocks as evidence of a biblical flood, and others for the movement of continents over time. A Pagan may hesitate to draw clear distinctions between the moral obligations we owe humans and non-humans.

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<sup>&</sup>lt;sup>19</sup> Sire has 'what is the meaning of human history' which I have included in Q2.

<sup>&</sup>lt;sup>20</sup> A period of geological time in which the rock sequences are indicative of the land being underwater around 400 million years ago.

Each idea held within the worldview does not exist in isolation, each is connected to and intertwined with others. DeWitt (2010 p.7) likens this to the interconnections of a jigsaw puzzle, visually represented by the following illustration of Aristotle's worldview:

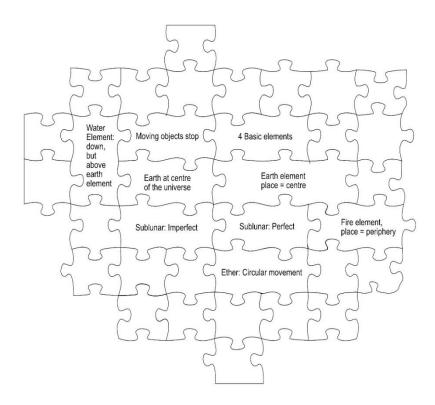


FIGURE 1 JIGSAW WORLDVIEW (MARTIN WINCHESTER AFTER DEWITT 2010 P10)

This interconnectedness of worldview parts suggests there is a need for the parts to be coherent with one another otherwise the pieces will not fit together. It also means it can be difficult to change or modify elements of the worldview because each depends on the others around it; worldviews are not modular, they are a complex arrangement of understandings, ideas and consequences existing more or less in equilibrium.

Many worldviews are considered to be traditional, such as those pertaining to longstanding religious sects - for a long time these were the only worldviews that existed. However, as societies have met, merged (willingly and unwillingly) and spread globally, many modern

worldviews are "a complex amalgam of a wide variety of beliefs, attitudes, ideals and practices – a typical modern worldview will often be highly personalised" (Benjamin 1990 p.86). The highly personal answers to those deep questions of existence matter to the individual. An important consequence of this is that if we are to respect religious beliefs because they are fundamental to an individual, then it does not matter how many individuals might subscribe to that worldview. Benjamin (1990 pp. 92-93) states that 'a person's commitment to a particular worldview and way of life is identity conferring [...] a particular world view and way of life determines who we are and what we stand for'. The fact contemporary worldviews are more personalised does not indicate that the worldview is inherently less valuable on that basis. If someone cares enough to act on it, then it matters. Worldviews are integral to identity.

Although the concept of a worldview is ostensibly value-neutral, any particular worldview itself will be inevitably valued differently by others who do not share it. Benjamin (1990 p.92) points out that the concept of worldview is helpful in explaining why people disagree on moral issues, but sadly cannot resolve the differences. One of the enduring problems between religious and non-religious worldviews is over the presence of the transcendent. Additionally, for us in the 'West', a worldview that does not allow for persons holding an opposing worldview to be accorded basic respect would be difficult to recommend. The 'scientific' paradigm, which is also part of our 'Western' worldview, also holds to some basic, reproducible, facts about the observable world which underpin modern medicine and technology.

Because areas 'covered by a world view are those parts of life we take for granted, never imagine questioning and cannot envision decent, moral people not sharing' (Luker 1984) exposure to other worldviews are profoundly difficult to manage. People of similar capacities

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and education can disagree vehemently about the same issue – for example the moral status of the fetus and abortion (Warren 2013, Strong 1997, Koenig, Harold G. 2006). This was the subject of Luker's (1984) observation that differing worldviews contain different rules about how one should approach and assess facts such as when human life begins and the *significance* of human life. This difference leads to incommensurably different interpretations of acceptable treatment of the human fetus. Because of the interlinking nature of the parts of a worldview it is not only beliefs about the start of human life, but also about motherhood, the role of the state, gender roles, female autonomy and experiences such as rape, loss of children and family relationships that all inform the opinion taken.

People at the edge of two worldviews, such as gay practising Christians and practising Catholic feminists, may have a worldview that seems incongruent and incoherent, and such colliding worldviews can be difficult to live in. People are all at different places in modifying and adapting their worldviews, and it is not so simple as choosing to reject one area and replace it with another.

#### 2.1.9 Pluralism and relativism

I assume that a normative ethics is possible within NHS healthcare and do so within this thesis' context. However, given the incommensurability of different beliefs about, for example, the value of embryonic life, it is inescapable at this point to briefly raise the issue of moral relativism.

Despite many years of philosophical reasoning, it is still apparent that different groups of people (from entire nations to much smaller groups) have considerable moral diversity (Häyry 2005, Gbadegesin 2013, Beauchamp, Childress 2012 p.24). As a consequence of this observation, metaethical moral relativists suggest there is therefore no objective,

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universalisable and agreed upon ethical standpoint from which we can apply terms such as good or bad cross-culturally. Thus, there is no absolutist or universalist morality and the best we can do is argue it from our own, culturally determined, position. The characteristic stance of moral objectivists, on the other hand, is that there is just such a universal morality. Theirs is generally an adversarial approach; that is, objectivists consider that moral disagreements arise because one position is not as well-informed of the facts or reasonable as the other. Such a view hinges on being correct that one is right in their assertion, and everyone else is wrong (Gowans 2018). However, as the extensive literature in ethics shows, well informed and reasonable people (even within a similar cultural paradigm) do frequently disagree.

This conflict can also create a full moral scepticism that denies there can be any moral claims at all (Häyry 2005). Although this is a valuable reminder that if we personally had been born in another time or place, we would have likely held a fundamentally different worldview- it also seems rather frightening, given that exposure to relativism can encourage people behave in immoral ways (Rai, Holyoak 2013).

The existence of moral diversity does not itself imply there *is* no universalisable or more moral way of behaving, merely that such an agreement has not yet been forthcoming. It is notable that even across different societies there are some agreements, such as prohibitions on theft and killing and other rules which promote charity and truth telling, for example. Haidt (2013), who addresses the issue that people tend to make judgements first (based on

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moral psychology) identifies six such commonalities;<sup>21</sup> although there are disagreements on when and to whom the rules apply, they are nevertheless fairly standard.

Several ways of mediating between objectivism and scepticism are suggested, and one of the better known is the 'pluralistic relativism' of Wong (1995).<sup>22</sup> In pluralistic relativism more than one morality can qualify as a genuinely moral, but certain objective constraints about the biological and psychological nature of humans must limit which moralities qualify (Wong 1995 p.378). Wong defines this as *naturalistic* in the sense that it recognises real human traits and needs as being central to an effective morality. An acceptable morality ought to lead to a co-operating society, enable persons to seek to fulfil their aims as a person, and needs some objective truths about the capacities of different types of people- for example, false beliefs about the capacities of different genders should not shape the moral rules (Wong 1995 p.387). These give grounds on which to argue whether a particular way of life incorporates an acceptable morality. This is the position I broadly adopt in this thesis (although I promote a particular normative approach from chapter four onwards), whilst also recognising that the demands of medical ethics may include some particular moral demands that would not apply more generally (Beauchamp, Childress 2012 p.5).

## 2.1.10 The changing nature of religion, a sociological perspective

As religion is a socially embedded phenomenon, it is worth briefly placing contemporary religion in the current sociological context. Sociological analysis of religion, in itself, does

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<sup>&</sup>lt;sup>21</sup> Care/harm, fairness/cheating, loyalty/betrayal, authority/subversion, sanctity/degradation (Haidt 2013 chapter seven) and liberty/oppression (Haidt 2013 chapter eight). Different groups prioritise and adopt from this range in different ways.

<sup>&</sup>lt;sup>22</sup> Beauchamp and Childress assert similar about their 'common morality' derived principles (Beauchamp, Childress 2012 pp.420-421).

not reflect whether particular changes have been ethically for the better or worse. Instead, understanding the reality of religion and medicine, within its context, enables ethical decision making in light of religions as they are experienced by people in the early 21<sup>st</sup> Century. Religions change and fluctuate in response to the culture in which they exist; being able to identify that religion may not necessarily resemble the characteristic forms of a century ago is useful for medical practitioners who may interact with contemporary religious patients.

A traditional view of religion is one that follows the familiar stories and behaviours of the Abrahamic religions. In the 'Western' countries, including the UK, this has a particularly (Protestant) Christian flavour (Smart 1995 p.37). This version of religion involves regular attendance at buildings of worship, the words of a holy text, sexual purity, sanctity of life, the concept of sins, and an overarching (male) creator divinity represented by saints and prophets and mediated by trained leaders (Harvey 2011 pp.206-207, Aldridge 2013 p.31, my own experience being raised in a Christian family). This, of course, is a simplification, but simple discussion with many people in medicine and beyond confirms this is the general understanding and expectation (D, personal communication 2015).

However, sociologically speaking, this traditional view may be becoming less accurate, due to the advent of 'modernity', and the understanding of other cultural and religious beliefs becoming more widespread. Modernity is characterised by the complex interplay between the growth of reason accompanied by rejection of tradition, an increase in notions of individual liberty, technological advance (progress), secularisation, increasing capitalism, nation-states, colonialism, democracy and education (Giddens 1991 p.15, Goodin, Bennett 2013).

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Relevantly, both medicine and religion changed during modernity. For medicine, illness and death became increasingly isolated (into hospitals, for example), understandable (thus predictable) and specialised; the preserve of expert (rational) physicians and scientists (Bauman, Z. 1998). For religion, there was an increasing fragmentation of authority between a single version of God, the various denominations and smaller churches; people paid more attention to what seemed important in the here and now, than any duties to the unverifiable. Different forms of religion become choices of identity, rather than the overarching essential rules that applied to all (Heelas, Martin et al. 1998). An increasing emphasis on individual and rational choice forms part of both medicine and mainstream religion. For example, 'the decline of institutional determination of life choices and instead the reflexive reconstruction of identity. What the traditional used to demand has transformed into lifestyle options (Heelas, Martin et al. 1998 p.5).'

For many sociologists, this period of 'modernity' is being, or has been replaced, by a phenomenon termed the 'postmodern' (Lyotard 1984). For example, post-modernity can be characterised as a process of de-differentiation.

'1 a refusal to regard positivistic, rationalistic, instrumental criteria as the sole or exclusive standard of worthwhile knowledge

2 a willingness to combine symbols from disparate codes or frameworks of meaning, even at the cost of disjunctions and eclecticism

3 a celebration of spontaneity, fragmentation, superficiality, irony and playfulness

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4 a willingness to abandon the search for overall or triumphalist myths, narratives or frameworks of knowledge' (Beckford 1992 in Heelas, Martin et al. 1998 p.4).

For others, the current era remains a direct part of modernity itself, termed 'Liquid modernity' by Bauman (2000, 1989) and as 'High Modernity' by Giddens (1991).

Zygmaunt Bauman (1998) notes that an inescapable feature of contemporary society is that it is highly fluid, capitalist and consumer driven. Traditional certainties and ways of life are subject to change and fluctuation. In this environment, religion must market itself to consumers, be they consumers of social sanction, seekers of meaning, or, importantly, those (like the poor) disenfranchised from a rapidly changing market of ideas and goods (Bauman, Z. 1998 p.73). The apparent growth of more extreme sects and cults (Bauman, Z. 1998 p.74) can be interpreted as a result of a search for personal certainty, amidst both a general mellowing of, or rejection of, formerly mainstream beliefs. Alongside this, people who are in globally displaced or immigrant communities use religion as a way of maintaining identity in a changing or difficult environment (Naidu 2016, Eghdamian 2016, Kogan, Fong et al. 2019).

It is not the case that religious adherence in modernity necessarily turns it's back on all the features of older forms. The US based – thus not directly transferrable to the UK- National Survey of Youth and Religion (NSYR) surveyed the religious beliefs and practices of American teenagers (The Association of Religion Data Archives 2003, Smith, Denton 2009). Although the young people surveyed tended to see religion as important but not a priority, many teenagers still attended traditional religious services and indicated religion and faith were significant parts of their life. Most among those, Smith and Denton observed, followed their family religion – the traditional mode of religious transmission. Few appeared to be

the 'seekers' hypothesised by others (Smith, Denton 2009 pp.260-261), although the mainline traditional Christian and Jewish beliefs were in decline compared to the religiosity of (the more modern) black or evangelical protestants.

Precisely what these teens believed was often nebulous and confused (2009 p. 262) and the authors came to call this phenomenon 'moralistic therapeutic deism' (MTD) (2009 pp. 162-163). MTD represents a homogenised understanding of a largely uninvolved creator God who wants people to be good to each other and to pursue happiness and personal peace as a goal. God may help resolve problems, and good people go to heaven on death. In the follow up work, *Souls in Transition* (Smith, Snell 2009), the authors revisited the former teenagers, now young adults. Alongside numerous, traumatic stories of coming of age in America (with attendant racism and poverty), many of these themes returned. Among them the authors observe a 'cultural' victory of mainline Protestantism 'individualism, pluralism, emancipation, tolerance, free critical enquiry and the authority of human experience' (a kind of MTD), even as adherence to mainline Protestantism as a specific religion declines. The values above permeate both secular and cross-religious thought among many of the emerging adults surveyed (Smith, Snell 2009 p.289). This diluted version of belief does support Bauman's suggestion of 'mellowing' (Bauman, Z. 1998 p.74).

This observed fluidity of contemporary religion does not mean any current religion is not a 'real' religion, is not critically important parts of the lives of some who adopt them, or not worthy of ethical seriousness. It merely means that they are the 21st century form of religion. Regardless of whether the changes in religious adherence and observation fall into something best characterised as either a Modern or Post-Modern period, what matters most for this thesis is that they have meaning for those who follow them. The forms of religion are also likely to continue to change over time. This makes it ethically relevant to take the

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focus away from well known, specific, traditional religious groups (such as large denominations of the Abrahamic faiths) when considering accommodation, and instead to consider what is experienced as being of religious importance by contemporary individuals and communities.

## 2.2 Paganism – an introduction

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Although this thesis is not a work of Pagan ethics or social anthropology, it uses the unfamiliarity of *Paganism as religion* to explore conventional approaches to accommodating religious beliefs. The purpose of this section is to introduce some key beliefs and practices of modern Pagans in this context, which I will use to construct example cases in chapter three. The description is necessarily brief and thus incomplete. For this thesis, the following paths as practiced today are classed as being part of Paganism; Wicca and related forms of witchcraft, Druidry, Heathenism, and eclectic Paganism. These should be seen as examples, not as restrictions.

Historically and often pejoratively, the term *pagan* (and by extension paganism) was used to indicate anyone not part of Christianity, or at least part of an Abrahamic faith (Horak 2016). In this thesis, where pagan (with a small p) is used, it refers to these historical beliefs. Sometimes a distinction is made between modern Paganism and this classical understanding by calling modern variants neo-Paganism, and other scholars cast the net wide and include all indigenous and classical religions as pagan (York 1995, Harvey 2011). Nowadays, 'Paganism' is broadly accepted as an umbrella term for a variety of different beliefs which share common themes. Harvey suggests that 'Pagans celebrate the natural world and encourage a sense of belonging in it' (Harvey 2007 p.1) and also speaks of Paganisms rather than a single Paganism. There are many different sets of belief and practice

in Paganism – often referred to as paths or traditions- which have some commonalities with each other, much like Unitarians and Roman Catholics have very different beliefs and practices yet are both broadly Christian. Pagans tend to be individualistic and reject the kind of dogma that characterises the Abrahamic religions (Manning 2010); there is no single 'sacred text', or religious authority to which all Pagans can refer -nor would want to. Any individual will, though, likely have their preferred sources.

Paganism does not always receive a welcome from members of other religions and the public in general. In part this is because Paganism doesn't always seem to follow the 'Western' 'rules' of religion (it is not generally monotheist, often lacks a clear priestly hierarchy and a written holy book). Evangelist Christians in particular (Harvey 2011 p.211), condemn Paganism as not only a false religion but claim that Pagans are involved in devil-worship, black-magic, human and animal sacrifice (Pike 2001 chapter three). In the UK, fears about manipulation of vulnerable people, sexual activity, nakedness and Satan caused occasional backlashes against Paganism, often fermented by the press (Hutton 1999 chapter 13). 'Satanic Abuse' scandals achieved some notoriety in the 1990s, although subsequent inquiries found no evidence of such abuse linked to Paganism. Instead, there were some few people who had used occult symbolism to terrify victims, over-zealous 'therapists' and a number of devastated families wrongly accused (Waterhouse 1994, Hutton 1999 p. 372, Harvey 2011 p.212). Horror movie portrayals of black-magic and creepy rituals feed into sensationalist media portrayals and scare stories to which the non-Pagan-inclined public are exposed, which shapes discrimination (Tejeda 2014). Emma Restall-Orr, a well-known Druid writer, speaks of Christians shouting a quote from the bible 'thou shalt not suffer a witch to

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live', <sup>23</sup> of people accused of 'bringing the devil into the workplace' and of a child put into the naughty corner at school for 'lying' – after he told his teachers the story of a Druid ritual at Stonehenge he had attended with his parents (Restall Orr 2007 p.112). Many Pagans, myself included, have a person (or persons) who have asked them whether they worship Satan, sacrifice babies or dance naked. Some of these questions are asked tongue in cheek; some are more serious, even threatening. Unfortunately, the negative perception of Paganism has led many Pagans to be secretive about their religion because of the judgements that might be made by others (Tejeda 2014, Reece 2014).

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Over the last 25 years there have been changes; positive media representations such as through TV shows like Buffy and Charmed <sup>24</sup> in the 1990s have potentially altered perceptions (Berger, Ezzy 2009) although some Pagans dismiss these as 'Paganism as fashion' (Restall Orr 2007 p.16). Although an initial rapid surge in people identifying as Pagan is linked to the 'Teen Witch fad' of the 1990s, Paganism is still growing and maturing (Reece 2014). Pagans are seeing others take them more seriously and respectfully. The Pagan Police Association was the first of its kind in the UK (Pardy 2015), the Druid Network was the first Pagan religious organisation to be granted UK charitable status in 2010 (Druid Network 2014) and Pagan Pride holds an annual event in Nottingham (Pagan Pride 2015). <sup>25</sup> Paganism is a living faith in 21<sup>st</sup> Century Britain<sup>26</sup>.

<sup>&</sup>lt;sup>23</sup> Exodus 22:18

<sup>&</sup>lt;sup>24</sup> Both shows had female leads with agency in a contemporary fantasy setting – Buffy the Vampire Slayer's best friend was a witch named Willow, and the Charmed sisters were hereditary witches.

<sup>&</sup>lt;sup>25</sup> I attended in 2015, it has been running since 2009.

<sup>&</sup>lt;sup>26</sup> There is no UK NSYR equivalent. Very few teen respondents to the NSYR indicated they were Wiccan or Pagan (0.4 % in the first and consistent in the final wave) (The Association of Religion Data Archives 2003), The Association of Religion Data Archives 2008)

## 2.2.1 Paganism in the UK

Providing an accurate estimate of the number of Pagans in the UK is difficult. In the census of England and Wales (2011), 240,000 indicated they did not belong to the main religions (see table 2, above). Of those in the 'other' category 56,620 gave 'Pagan' directly as an answer (see table 4, below). Others wrote in their specific traditions, some of which can be considered under the Pagan umbrella, such as Animism, Shamanism, Druid, Wicca and witchcraft; including these brings the number to 77,000. This figure makes it the 7<sup>th</sup> largest religion in the UK at between 0.1% and 0.2% of the population.

Academics and Pagan groups estimate the true number to be much higher (Western Daily Press 2013).

Pagan following: Data from 2011 Census table QS210EW (Office for National Statistics 2013)					
Path / Tradition	No. in England and Wales	Path / Tradition	No. in England and Wales		
Animism	541	Shamanism	650		
Druid	4,189	Wicca	11,766		
Heathen	1,958	Witchcraft	1,276		
Pagan	56,620	TOTAL	77,000		

#### TABLE 4 PAGAN FOLLOWING IN THE UK

# 2.2.2 The nature of Pagans' religion and belief

'Paganism', as outlined above, is an umbrella term that is used largely out of convenience. There are relatively few academic publications on modern Paganism, as Pagan studies is still a small but rapidly growing area of academic interest. There are a great many non-academic publications- books, internet sites, television – that cover Paganism and Pagan paths. The eclectic mix of sources illustrates the difficulty of providing a narrow definition of what it

means to be 'Pagan'. Some may be initially attracted through television shows (Davy 2007 p.196, Berger, Ezzy 2009) or through a love of fantasy literature or folk tales (Harvey 2011 p.177-179, Hope, Tom, Jones 2006), and it is through these representations of Paganism that many people begin to explore Pagan belief systems, and from which many will go on to develop their belief and practice. Although a number of contemporary Pagans may have Pagan parents or grandparents (who came into Paganism during the 1950s and 60s and after), Paganism remains something to which most of its followers were drawn and actively chose as adults.

The descriptions below are drawn from academics of Paganism, and from publications targeted at exploring and learning the various Pagan paths.

### 2.2.2.1 Key shared features

#### 1180 The Otherworld:

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A belief in something that may be anthropologically termed an *Otherworld* (Greenwood 2000 pp.23 & 27, Harvey 2011 p.160, Davy 2007 p.25) which is not usually or directly visible to the ordinary world; although it may be connected to it or part of it. All beings are in some way linked to the *Otherworld* and each other (through deities, matter, or other mysterious forces) although some people are more adept at experiencing this *Otherworld* through ritual, psychological or shamanic practices. The *Otherworld* acts as both a place, and as a concept which influences the working of magic and self-understanding. The *Otherworld* is not analogous to the Heaven (or Hell) of Christianity - although for same Pagans the ancestors and the dead might reside there in some form.

#### Fully embodied lives:

A belief that humans are not spiritual beings 'trapped' inside rebellious or impure bodies until they ascend (or descend) to another existence based on their behaviour, but that humans are fully embodied lives with pains and joys, needs and wants, and responsibilities to the existing world (Harvey 2011 p.1). Sexuality and physicality are not seen as things inherently shameful, but as things to be celebrated (Pike 2001, Harvey 2011 p.51) in contrast to the beliefs and/or behaviours shown by religious teens in *Soul Searching* or *Souls in Transition* (Smith, Denton 2009, Smith, Snell 2009) or detailed in the traditional Abrahamic scriptures.<sup>27</sup> Concepts such as 'original sin' have no place in Paganism so Pagans don't seek a religious 'salvation' (Harvey 2011 p.216). The main feature that distinguishes New Age spirituality from Paganism might well be this belief- for the New Ager the focus is on 'light' and spiritual transcendence - and the ultimate release from spiritual negativity (Harvey 2011 p. 213). For the Pagan, '[t]he centre of attention...is embodied life and participation in the living world' (Harvey 2011 p.215).

#### Veneration of the natural world:

A recognition of the importance of, and celebration of, the natural world and cycles such as the lunar month, the seasons, birth- life – death (Taylor, B. 2010, Cragle 2017, Tejeda 2014, Ezzy, Berger 2009). This appreciation of and respect for the 'natural' includes rocks, landscapes, animals and plants. Non-humans are not simply *matter* but are also in some sense entities; it is therefore necessary to acknowledge the interests of non-human beings (Davy 2007). This belief stimulates the strong commitment of many Pagans to ecological

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<sup>&</sup>lt;sup>27</sup> That such beliefs are part of the religion is accepted, though to what extent this affects practice would be a useful empirical addition to the literature.

causes. It is worthwhile noting that although this belief leads some Pagans to be vegetarians, others acknowledge that taking life for sustenance is a part of life and remain meat eaters – albeit often meat eaters with an active concern for animal welfare.

#### Interconnected ethics:

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Moral consideration is not only extended to other humans, but to other elements of a vast, interconnected web-like whole of existence from animals and plants to the rocks and processes of the planet itself. Harvey expresses this by referring to 'all our relatives' (Harvey 2011 pp.1, 221) which imposes ethical obligations on humans to treat non-humans as interconnected family, even if not in the same way as our fellow human relatives. A fundamental ethical rule is that you should not (unnecessarily) harm others both human and non-human. This can be seen clearly expressed in the *Wiccan rede* and its variants as 'though it harm none, do as you will' (Harvey 2011 p.100). Will here is not equivalent to 'want', more it is a sense of will as a considered judgement and active choice, although there is little specification as to what constitutes harm (Greenwood 2000 pp.200-201).

# 2.3 Specific Pagan paths

## 2.3.1 Witchcraft (Wicca / Traditional / Feminist)

The development of Wicca (also Witchcraft or 'the Craft') has been well documented by historian Ronald Hutton (1999). It has early 20<sup>th</sup> century origins, a magical system inspired by the 18<sup>th</sup> and 19<sup>th</sup> centuries' fascination with occultism and freemasonry, and Romantic literature harking back to classical Goddesses and the rejection of urbanisation. Gardnerian Wicca is the original form, but since Wicca began it has been modified and adapted by different practitioners into a variety of forms, including Alexandrian Wicca, Celtic Wicca

(incorporating a strong cultural connection to Celtic deities and traditions) and Dianic Wicca (a female-only form)(Harvey 2011 p.35, Davy 2007 p.151-155).

Wicca looks more favourably on women than the major world religions, placing the female principle as at least equally valuable in terms of world creation (Harvey 2011 p.38). The example of creator Goddess and God as a union represented a change from the unilaterally powerful monotheistic male god of, for example, Christianity, a rejection of the established order. For some branches of Wicca, the female (procreative) aspect is made predominant, and this variant grew in popularity with feminism, venerating 'feminine' traits as positive, albeit essentialist (Harvey 2011 p.42).<sup>28</sup>

#### 2.3.1.1 The Goddess and the God

A key element of Wicca is a belief in a procreative or creative deity that is represented by either a female primary (Goddess- centred), or a male-female pair (Traditional). The pair may be viewed as controllers of, or manifestations of, natural forces such as creation, fertility and destruction (Davy 2007 pp. 18-21).

In the Wiccan worldview, the female might be portrayed in 3 aspects, maiden, mother and crone, representing various life stages and the traits that are believed to correspond to these stages (Davy 2007 p.18, Harvey 2011 p.38, Manning 2010). The maiden represents both purity

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<sup>&</sup>lt;sup>28</sup> More recently the idea that in witchcraft, women should be identified with a set of 'feminine' traits in polarity to 'masculine' traits (Greenwood 2000 p.102) has been subject to challenge (Oboler 2010, Hedenborg-White, Tollefsen 2013). There is a move by many Pagans away from gender essentialism; there are now a variety of Wiccans practicing an array of traditions as solo practitioners, or in all female, all LGBT, all male or mixed groups. However, Zusanna Budapest, developer of Dianic Wicca, has been vehemently criticised by Pagans (but also supported by some) for the exclusion of \*trans women from female only rituals (Coyle 2011, Kaveney 2011, Pitzl-Waters 2012). In modern Witchcraft, hetero-normativity and gender-essentialism are being challenged, with many Wiccans seeing men and women as capable of experiencing a duality of masculine and feminine qualities (Cragle 2017 p.83).

and sexuality, creativity and kindness are ascribed to the mother, and the crone is representative of old age, wisdom and magic. Although the Goddess is central to Wiccans and may be invoked as simply 'the Goddess', other deities can be invoked in association with, or as aspects of the Goddess. This could include female deities from the Hindu, Norse, Celtic, Egyptian or Greco-Roman pantheons, such as Kali, Freya, Danu, Isis or Diana (Harvey 2007 p.55, Starhawk 1999 p.102). These various goddesses from historical and world religion may be linked to or associated with the various elements of the Goddess personality, for example, the Egyptian Isis, or alternatively, may be seen as independent elements of the female force. This could be evidence of Beckford's de-differentiation and eclecticism (Beckford 1992 in Heelas, Martin et al. 1998 p.4, above at page 50).

Dependent on whether the Goddess is cast as primary, or as part of a pair, the male element may be presented as an equal or as a temporary consort. The male figure is frequently Pan (a Greek God) or Cernunos (putatively Celtic), horned Gods with animal-esque features (Davy 2007 p.19-20). This association with a figure that clearly resembles portrayals of Satan, and is associated with sex, hunting, wildness and sometimes, death, causes consternation to some Christians.

The centrality of the Goddess is represented by the important ritual of 'drawing down the moon' (Davy 2007 pp.76-77, Harvey 2011 pp.39-40, Greenwood 2000 p,96) in which the goddess is 'brought down' into the body of the practitioner. Those who have undergone the rite often speak of experiencing a profound transformation as a result of the experience. This reflects the strongly experiential dimension of Pagan belief.

## 2.3.1.2 *Magic*

For Wiccans (and some other magic practitioners) humans -or some humans- have the ability to tap into metaphysical forces to work 'magic' – which can be used for destructive 61

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or creative purposes. Instead of accepting the will of or asking for mercy from a deity, as might occur in traditional Christianity, magic places the ability to affect the world in the hands of the practitioner (although they may request the help of a deity in so doing). Often, the magic is worked to 'raise energy' - energy thus raised can be directed towards a goal such as healing, self-change or protection (Davy 2007 p.62, Harvey 2011 chapter 6, Greenwood 2000 pp.27, 124).<sup>29</sup> In practical Wiccan magic there is the idea of consequences. In this concept, acts such as magical cursing performed by the individual return to them, particularly bad ones (Greenwood 2000 p.200). In common with divine 'punishments' in many other religious belief systems, this serves to discourage harmful actions and promote the good (as might the concept of hell versus heaven, or the 'borrowed' concept of *karma*). For some Witches there is a concept of threefold return- what one does comes back threefold- including the bad (Davy 2007 p.166). Some practitioners of Wicca consider that it is part and parcel of the path to be involved with the working of magic (although this varies in extent) and that the two are inseparable. Others claim that Wicca does not in and of itself require the adherent to practice magic, merely to hold the corresponding world views. There are also numerous workers of magic - such as hermetic or cabbalistic magicians- who are neither Wiccan or Pagan (Harvey 2011 p.84).

## 2.3.1.3 Wiccan festivals and 'The Wheel of the Year'

Numerous representations of the wheel of the year are available. The following is largely derived from *Contemporary Paganism* (Harvey 2011). Four of the Sabbats are determined by the quarters of the year (Solstices, Equinoxes) and four fall between the quarters. These are

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<sup>&</sup>lt;sup>29</sup> Hutton reports an alleged massive energy ritual that took place among Wiccans and hereditary witches during the Second World War – directed at protecting Britain from Nazi evil.

often roughly compared to early Celtic festivals; Samhain (usually pronounced sow-en) corresponding to Halloween, Beltane representing May day, Lugnasadh (Lunasa) broadly correlating to Harvest, and Imbolc – the start of spring. These festival days are not constrained to Wicca, surfacing in many of the contemporary Paganisms and New Age spiritualities, and various days may be held in varying regard by different practitioners. In Wiccan mythology, the seasons of the year correspond to the Goddess' progression through aspects of maiden, mother and crone to be reborn at the end of winter. Similar seasonal mythology is incorporated into Druidry and eclectic Paganism, reinforcing the connection with the Earth and natural phenomena perceived to be absent in established religion.

## 2.3.1.4 Witchcraft symbolism and iconography

Pentagrams (a symbol in use for various parts of history by diverse cultures) are at least partly representative of the five elements and are one of the first things many people think of when thinking of Paganism and magic. As well as the elements, the pentagram can represent connectedness of all things, the horned God and protection from negative forces (Greenwood 2000 p.85, Hutton 1999 pp.67-68, 71). Despite negative public associations with devil-worship and 'black magic', the pentagram does not represent these - including point down. Point down pentagrams are used to indicate a Wiccan's level of initiation (Crowley 1996 p.195).

It is common to find representatives of the four (or five) metaphysical elements of earth, air, fire and water (with possible inclusion of spirit) in Wiccan and other Pagan ritual. They may be represented by candles, water, stones, salt or other place-holders (Davy 2007 pp.64-65). Group rituals are frequently conducted in circles, and circles are similarly invoked by solo practitioners as a sacred or working space (Harvey 2011 p.44). Correspondingly, there is use of directions (North South East and West) in ritual practice (Crowley 1996 p.45,

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Greenwood 2000 pp.84-85). The use of elemental symbols as spiritual tools, tarot or similar cards, and objects such as wands and the performance of music and chants are also common to many Pagans (Pike 2001, Davy 2007). Also, Wiccans and other Pagans may also use natural items such as wooden wands and wreaths of plants in worship, ritual or magic. For some, different woods and plants hold particular properties and associations, so would use a hazel wand for different purposes than one made of oak, or a blue candle for different spells to a red one (Starhawk 1999 Tables of Correspondences). Items that are used for worship and ritual can be highly individualised, even unique (particularly true of 'found' objects such as a particular pebble or feather). Because these objects are considered special, potentially 'sacred', there may be rules governing who can handle them and when.

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The Goddess herself may be represented in several forms in icons, pendants or other jewellery, tattoos, artworks and statuettes. Often this is a threefold form, such as through the triquetra or in symbolic moon phases. The moon may hold particular relevance for Wiccans and Pagans through historical association of the feminine with the moon, and that other 28 day cycle, menstruation (Davy 2007 p.77). The Goddess may also be portrayed as a female figure, often with an exaggerated, perhaps fecund, belly styled after female figurines of the palaeo- and neo-lithic; or she may take the form of Goddesses from other religions.

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One element of Pagan ritual that is often sensationalised is 'The Great Rite' (Greenwood 2000 p.104). This ritual is a representation of sexual union between the Goddess and the God – a potent creative / energy raising / fertility ritual. Fictionalised accounts of the symbolic unification of male and female essences often draw on the salacious and sexualised element of the act (there is one in the 2006 film version of Dan Brown's 'Da Vinci Code'), but this is far from reality. The union of male and female is generally portrayed mundanely through the knife (phallic and male) and chalice (yonic and female)(Greenwood 2000 p.151).

Despite popular representations to the contrary, actual (as opposed to representational) blood and sex are only occasionally, if ever, involved in most Wiccan ritual practice (Greenwood 2000 p.104).

Outside of this ritual, knives and cups are important religious and magical symbols. Many Wiccans (and other Pagans) will carry an *athame*, a ritual knife (Davy 2007 p.63); for some it is important that this is kept on or close to the person. Many Wiccan and Pagan altars will feature a cup or chalice, and drinking from the cup can be an important element of Pagan ceremonies.

## 2.3.2 Druidry

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Britain has a strong Druidic tradition although modern Druids are found all around the world (Pagan Federation 2015).

The original druids were the priests (and priestesses), wise-people, healers and judges in pre-Roman Britain; their existence and some of what they did is present in writings about them from contemporaneous, or near contemporaneous Roman authors. For example, Julius Caesar linked *druides* to human sacrifice *in extremis* and to considerable status as learned and wise men; Siculus spoke of *drouidas* as soothsayers and *bardous* as poets; and Tacitus described the bloodthirsty *druidae* as cursing the Roman invaders of Anglesey (Hutton 2009 pp.2-13). More recently, Druidry re-developed during the 18<sup>th</sup> and 19th century. People such as poets, Christians, reformers and folklorists found the idea of being both learned and connected to the land appealing, taking on the name of the wise and venerated 'druid' and adopting a variety of different practices (Hutton 2009). Some formed Christian charitable orders, others participated in esoteric Masonic rites or sought to restore ancestral traditions of storytelling and song (Harvey 2011 p.18). Although some of the older

druid charitable orders still exist and there are also Druids from non-Pagan religions who find druidic beliefs in keeping with their own faith (Jennings 2002 pp.83-84), my concern is with the modern Pagan Druidry which has grown out of this history.

Although Wicca draws on the concepts of 'Mother Earth' and the wheel of the year, in Druidry there is a particularly strong focus on being connected to the landscape and to natural cycles. Whereas Wicca's Goddess has a particular affiliation with the moon, Heathens may associate women with the warmth of the Sun, and many other Pagans focus on the earth, Druids seek to recognise all of these heavenly bodies (Jennings 2002 p.83). Druids will often hold ceremonies, especially the public ones 'in the eye of the sun' – in daylight (Harvey 2011 p.20). That is not to say that other Pagans only do rituals by night or the Druids only by day, but the Sun from whom all life on Earth<sup>30</sup> depends is a strong element of Druidry.

Druidic stories and mythology derive from Celtic tales, British and Irish folklore and Arthurian legend. Most Druids recognise that these stories are subject to varying degrees of alteration and outright fabrications over the years but still find the truths within compelling.

#### 2.3.2.1 Awen

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Central to much Druid belief is the concept of *Awen*. *Awen* loosely translates as inspiration, but it represents a 'flowing spirit' (Harvey 2011 p.20) or 'all-pervading life force' (Jennings 2002 p. 84). Druidic ceremonies often include an invocation and expression of Awen, chanting Awen or 'AIO' as a means of connecting to and experiencing this force (Harvey 2011p.21). Awen may be seen as flowing from a deity, as the source of Spirit or as arising from

<sup>&</sup>lt;sup>30</sup> With the exception of some bacteria.

Mystery (Harvey 2011 p.18). Awen represents the transcendent, but is not a deity in the sense recognised by Abrahamic norms.

Our current existence is in a 'web of life' formed from the multiple relationships of living things and a process of rebirth (Harvey 2011 p.28). For some druids this is known as the circles of *Abred*. The living things in *Abred* emerge from the circle of *Annwn*, a 'chaotic simmering cauldron containing all potential forms and manifestations' (Harvey 2011p.28). Beyond *Abred* is the circle of *Gwynvid* – a state of perfection for all things, and both beyond and through everything is *Ceugant*, the causative – perhaps divine – realm. Just as Wiccans embrace the symbolism of threes in connection with the Goddess, *Annwn*, *Abred and Gwynvid* can be represented by the triquetra, triskele and borromean rings.

#### 2.3.2.2 Tree lore & Shamanism

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Another element of Druidry is the use of tree-lore which builds a complex web of associations, meanings, medicines and ecologies. The knowledge of trees might be practical – for example knowing the properties of the timber for building and how a species fits within an ecological web; or it might be spiritually relevant – a tree's links to moods, life stages or deities might be used in divination or guidance. Tree lore (Order of Bards and Druids 2014) is often associated with an ancient writing system known as Ogham, and many Druids might use Ogham in rituals or worship.

Druids also use a variety of what can be called shamanic practices. These might include sweat lodges, fasting, isolation, trance inducing music and chanting, or meditative techniques - all of which have the purpose of opening the self to the *Otherworld* or to redeveloping the relationship with this one (Harvey 2011 pp.26-27). This a particularly good illustration of the experiential dimension of religious belief.

### 2.3.2.3 Druid organisation

Many Druids recognise three separate, but mingling, grades of Druidry; the Bard, the Ovate and (perhaps confusingly) the Druid. Most followers of Druidry refer to themselves as Druids regardless of their stage on the journey. Rather like the way in which some Wiccan traditions have strict rules of initiation and others do not, some who follow Druidry may follow a long, many year apprenticeship to be called a Druid, whereas others do so by taking on the Druidic spirituality by other means (Taylor, Bron 2008 p.508).

Becoming a Bard was once the first step on the path, but may now (like the others) be a specialism for some or a simple element of the whole. Bards learn and tell both traditional stories and new ones – transmitting lore and celebration through performing poetry, songs and music. Harvey speaks of Bards as not only listening in order to memorise songs and stories, but to listen to the ancestors, themselves, others and the Earth. In so doing, the Bard hears what is needed and finds the appropriate words or music for the occasion (Harvey 2011p.20).

The second grade is that of the Ovate (Harvey 2011 p.25). Like a Bard, an Ovate might be considered as someone on route to being a Druid, or Ovate skills might just be part and parcel of a particular Druid's religious practice. Ovates can be considered as the seers and mystics who listen to the *Otherworld* or to other than human people, but they are also users of knowledge and practical lore. Some Ovates use Ogham and tree lore as a meditative or divining tool (similarly to the way that tarot or Norse Runes might be used), others use conventional or alternative therapies to bring healing to the body and/or mind. Some Ovates take on the responsibility of initiating others into mystic parts of Druidry through meditation or shamanic experiences. Any one Ovate might use all, or none of these methods.

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The path of a modern Ovate might be that of a scientist, therapist or shaman, or more probably a little of each.

The third grade in Druidry is that of the Druid *per se*, drawing on the elements of the other grades as advisor, teacher, organiser and ritual leader (Harvey 2011 p.29). A Druid in this sense has skills as a Bard and as an Ovate, but also has the ability to organise and act decisively for and with others. Within the Order of Bards, Ovates and Druids (a large Druid organisation in the UK and beyond) Druids are the organisers of gatherings and festivals, facilitators of those who are already interested in Druidry and those who want to learn more. Druids may be the public face of their Order or Grove when dealing with both other Druid groups and people at large. Although Druids may be organisers or elected leaders, they are not an 'authority' figure and they remain accountable to their fellows on the path. Druidry – like the rest of Paganism – usually seeks a non-hierarchical and non-dogmatic structure.

### 2.3.2.4 Druid iconography and symbolism

Key elements of Druid religion are symbols such as the oak tree, Mistletoe and the grove of trees. These were observed by Roman commentators and the association with these is common today (Taylor, Bron 2008 p.508). Many Druids assemble into communities called Groves in recognition of this early association.

Stonehenge, Avebury and other stone circles are considered important sites of power and worship in many Pagan traditions. The same can be said of megaliths, barrows, burial sites and iron-age earthworks (Hutton 2009 chapter 12, Doyle White 2016). The sites themselves originally performed various, largely unknowable functions and many pre-date the pre-Christian druids themselves (some are much later additions). However, these sites have modern relevance as 'sacred' places (Doyle White 2016 p.348) for Druids and other Pagans, who perform personal and group rituals at them. Druids are often actively and sometimes

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controversially involved in protecting these places, and with how to understand and preserve ancestral remains (Harvey 2011 p.33).

## 2.3.3 Heathenry

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Modern Heathenry is polytheistic, and represents a return to, or interpretation of, pre-Christian Saxon, Norse, Icelandic and Germanic tradition (Harvey 2007 p. 55). Unlike the Wiccans and Druids, Modern Heathens have an extensive written record of pre-Christian practices, in the form of the Eddas and Sagas and Anglo-saxon poetry on which to draw (Duir, Hunt-Anschutz 2014). Archaeological evidence supports these writings – giving modern Heathenry a strong reconstructionist foundation. Some practitioners refer to themselves simply as Heathens, for heathen derives from a similar meaning to pagan from a Germanic rather than Latin root, but might also call themselves for a specific tradition such as Asatruar (followers of the Norse deities called the Asatru) or more broadly as followers of Northern (sometimes Viking) Tradition (Jennings 2002 pp.90-91, Cragle 2017 p.79).

#### 2.3.3.1 Gods, wights and ancestors

Heathenism is overtly polytheistic, incorporating the well-known deities of Norse myth such as Thor, Odin and Freya (Cragle 2017). The Norse pantheon itself contains over 100 deities (grouped into the Aesir and the Vanir), and also deities formed from the spirits of the landscape called *wights* (Jennings 2002 p.92). Local and family deities are also recognized – such as the *Disir* – female ancestor spirits. The *wights* of particular places – a river, a mountain, a home, are important and their permission needs to be sought for conducting rituals and other affairs in their space. In addition, Heathens recognise many other-than-human entities, such as elves, brownies and giants (Duir, Hunt-Anschutz 2014). The strong

inter-connectedness of the people with the land, and particularly the land of origin, is a strong theme in heathenism, which has led to some problems with racism and separatism (see controversy, below).

In Heathen cosmology, we live in a world (Midgard) that is one of nine, linked by the world-tree *Yggdrasil*. The conflicts between the entities of the nine worlds form the basis of much of Northern legend. The world tree itself (similar notions of a world tree can be found in other Paganisms) is constantly fed upon by the creatures that inhabit its roots and branches, yet constantly renewing itself as it nourishes those who feed there (Harvey 2011 p.54).

The *Norns* -specific female *wights* similar to the Greek Fates- dwell at the root of *Yggdrasil* (Harvey 2011p.55) the world-tree. Here they weave the threads of all lives in the nine worlds into the web of *Wyrd*. *Wyrd* is a network of fate, personal destiny and the weight of ancestral ties (Harvey 2011 p.56) through which individual acts can affect and be affected by other people, families or tribes over generations. (Jennings 2002 p.93) Because one's actions or inactions can have repercussions beyond the self and the immediate moment, oath taking and honour are particularly important to Heathens who place a strong emphasis on personal responsibility. This voluntary undertaking of responsibility to the Gods, self and others can be expressed through the idea of *Troth* (Jennings 2002 p.94) which shares an origin with the kind of serious promise implicit in *betrothal*.

The honouring of ancestors – either literal or those deceased but continuing to inspire – are important to Heathens (Doyle White 2016). The earliest Norse beliefs were that reputation – being remembered – was immortality, hence remembering those who came before secured their continued existence. The concept of *Valhalla* (for battle-slain warriors) and other places of afterlife were later additions but remain distinct from conceptions of Christian ideas such as heaven and hell (Jennings 2002 p.94).

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Beyond oath taking, some Heathens (particularly American Asatruar) follow Nine noble virtues. The virtues vary by source, but might be explained as Courage, Fidelity, Industriousness, Truth, Discipline, Self-reliance, Honour, Hospitality and Perseverence (Jennings 2002 p.94, Cragle 2017 pp.98-99).

#### 2.3.3.2 Heathen symbolism and ritual

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Perhaps the two most obvious symbols of Heathenry are Thor's hammer *Mjollnir* and a series of 3 interlinked triangles called a *valknut*. Many Heathens will use the hammer symbol even if their principal deity is not Thor, because the strength implicit in the icon – the vitality and energy of the world- is symbolic of Heathenry's strength and vigour and refusal to be bowed by invading Christians (Harvey 2011 p.59). The *Valknut* is often associated with Odinists (Harvey 2011 p.59).

Blots (*bloats*) were originally animal sacrifices made to Gods, entities or ancestors, honouring them and/or seeking their aid. Modern blots have replaced animal sacrifice with offerings of food and drink, but the feast remains. *Symbel* is ritual drinking often featuring mead, an alcoholic honey drink that is popular among many Pagans and has particular favour with Heathens (Duir, Hunt-Anschutz 2014). Offering a libation to the Gods, wights and ancestors is common (and, like mead, is often seen in other Paganisms).

Like other Pagans, Heathens acknowledge seasonal festivals, but many eschew the 8 festivals of Wicca and Druidry as late inventions. Instead they may focus on *Winternights* (the start of winter), *Yule* (midwinter) and *Sigrblot* (*the start of summer*) (Harvey 2011 p.58). Groups of Heathens, which may be called hearths, will also celebrate other festivals during the year – honouring a particular ancestor or God, or group thereof (Harvey 2011 p.59).

### 2.3.3.3 Heathen magic

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The practice of magic is not as central to polytheistic Heathenism as it is to Wicca. Ceremonial magic, *Galdr* is associated with the runes (Harvey 2011 p.61). Runes can imbue items, people and places with particular magical strength (Jennings 2002 p.95). Combined into complex *bindrunes* they can express potent ideas as well as magic (Harvey 2011 p.64). Runes may also be chanted and spoken during ritual (Harvey 2011 pp.62-63) or used for divination.

A more shamanic form of magic, *seidr*, had historical associations with sorcery, ostracized by association with the already marginalised tricksters, females and homosexuals (Cragle 2017 p.103). For some modern Heathens, contacting the *Otherworld* by these means is not part of the tradition, but for others *seidr* is being used increasingly as a label for positively viewed Heathen shamanism (Harvey 2011 p. 62).

## 1540 2.3.3.4 Heathen controversy

There have been instances of Heathenism and its icons being used by far-right and neo-Nazi organisations (ADL 2019, Cragle 2017 p.87, Harvey 2011 pp.66-67). Some branches of Heathenism do support the idea that one should follow a path which is born out of one's ethnic origins, reflects pride in one's ancestry, homeland and benefits one's own people, but the majority shun supremacist appropriation of these ideas (Jennings 2002 p.97). This has not prevented some Heathen groups objecting to those claiming to be Heathens if their backgrounds are not – at the very least – Northern European (Cragle 2017 p.88). Other Heathens will not find this to be a problem.

## 2.3.4 Eclectic Paganism

It probably cannot be overstated how varied Paganism is. A list of other paths and forms of Paganism would run to hundreds of items. There are those who claim descent from a line of practitioners of 'the Old Ways' – the Hereditary Witches. There are Ceremonial (or High Magick) practitioners – some few of whom are Pagan, some of whom are just workers of magic. There are those whose Paganism is firmly rooted in syncretic religions such as Santeria and Haitian Vodou, or in the religion of the indigenous Mexicans (Davy 2007, Harvey 2011, Tejeda 2014). One in particular is Eclectic Paganism which draws on many different paths.

A significant number of people identifying as Pagan do so without a clear path in mind (Jennings 2002 p.113). Eclectic Pagans take elements of different paths and none, formulating a personal belief set and accompanying ritual that, while unsupported by any one tradition, contains the necessary parts of a Pagan worldview (Davy 2007 pp.5,194). Of the Pagan paths, they most embody Benjamin's 'modern' 'highly personalised' worldview (Benjamin 1990 p.86) referenced in sections 2.1.7, 2.1.8. They also seem to most encapsulate the traits of modernity and indeed postmodernity as outlined by Beckford (Beckford 1992 in Heelas, Martin et al. 1998 p.4, see above p. 50) – they embrace something more than a fully secular approach to knowing, they are unashamedly syncretic, often playful and spontaneous (but not necessarily superficial) in their approach to their faith, and reject a single notion of a correct, overall myth. They are people who have felt themselves drawn to nature spiritualities and may have tried several different paths, finding none that feel right, or perhaps have objected to attitudes within some groups (Pagans are, after all, humans with

human vices). Over time eclectics may be drawn towards a more formal tradition as their

ideas solidify, or not. Many eschew 'formalised' elements in Pagan religion, such as degrees

of initiation in Wicca or the intermediary role of priest figures, as being too similar to the strongly authoritarian elements of beliefs such as Christianity or Islam. Eclectic Pagans might avoid literal or abstract deities altogether, and focus their beliefs on something like *Awen*, or *Wyrd* as concepts expressing interconnectedness. Many, if not most, are solitary practitioners with only occasional 'Pagan' contact with others (Reece 2014, Davy 2007 p.2, Hope, Tom, Jones 2006).

Eclectic Pagans are sometimes accused of lacking discipline or authority, guilty of 'picking and choosing' (Jennings 2002 p.113) or 'mixing and matching' (Rinallo, Maclaran et al. 2016 p.428) their beliefs. Like 'Sheila', the subject of Bellah et al's study of American life (Bellah 1985 p.221), eclectic Pagans can be seen as victims of the cult of individualism and consumerism, in that they believe a little of this and that. Whereas there are legitimate concerns about appropriation of ethnic and cultural beliefs out of their context (Davy 2007 p.167), eclectic Pagans have a point that there is more to truth than can be found in a single path; many include profound concern for environmental and social justice matters that have not been taken up by more traditional faiths (including some particular threads of Paganism). Gardner's Wicca, itself traceable to his experiences in Africa and India and to his Freemasonry (Davy 2007 p.126, Hutton 1999), began as one man's eclectic Paganism. Welldeveloped eclectic paths arise from exploring, testing and requiting different beliefs with each other, creating a belief system which is new and remains open to a constant process of refinement. Eclectic Pagans, perhaps more than the paths, challenge popular understandings of religion; they resist classification by restrictive definitions of religion, resist the notion of priest figures as gatekeepers to the sacred, embrace syncretism, and accept the validity of the beliefs of a very wide range of people (Aldridge 2013 p.205). In so doing they seem to me to exemplify what can be termed 'lived religion', doing religion as 'an

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ever-changing, multifaceted, often messy -even contradictory- amalgam of beliefs and practices that are not necessarily those religious institutions consider important (McGuire 2008 p.4)'... 'as messy as those lives may be in practice, individuals' lived religions are what really matters to them' (McGuire 2008 p.213).

# 2.4 Paganism and contemporary religion

There is a lack of empirical research into the followers of Pagans' actual day to day relationship with their faith (something akin to NSYR), which means it is difficult to identify Paganism's position within the contemporary religious landscape. The young adults of the USA also differ in experience from folk in the UK, in terms of the historical religious backgrounds and the current socio-political environment, making any extrapolations hard to justify. However, the modern Paganisms (for which read contemporary, rather than 'modern' in the sociological sense) undoubtedly share an individualist, liberal streak in keeping with other contemporary religious movements the NSYR reported and thus with general commentary on modern religion.

Unlike the general findings of the NSYR, in which young people who were religious tended to follow the religion of their families, Pagans (as far as is reported) tend to choose as adults.<sup>31</sup> It is possible that for contemporary Pagans the lure of the supernatural, magical and mystic elements of Paganism (represented by claims to have been drawn to Paganism through fantasy tales, folk literature and tv (Harvey 2011 p.176-184) may also be a search for

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<sup>&</sup>lt;sup>31</sup> An informal poll conducted by a (private) UK Pagan Facebook group, albeit a small sub-sample of the Pagan population, found that only 5% of the respondents had been raised in a Pagan or part Pagan household. The majority had been bought up Christian or 'nothing in particular' (https://www.facebook.com/groups/UKPagan 2020).

something to replace the 'disenchantment' of the modern world. Perhaps it is a rebellious rejection of the mainstream (white) Christianity of those countries in which Paganism has strongest pull (The UK, Northern and Eastern Europe, the USA, Australia)- a search for novelty; although claims to much older pre-medieval traditions suggest a need to anchor beliefs to something older and thus, perhaps perceived as more legitimate or stable (Harvey 2011 p.172). As the mainstream secularises, though, general concerns about personal growth and moral issues may not be sought out through religion. Both Christian Smith and some Pagan commenters notice that younger members may be disengaged with the more traditional practices of their religion (Smith, Denton 2009 p.262, Aboymadeofsky 2017), adopting the MTD, suggesting a need to understand the way young people engage with beliefs. With similar data to NSYR the relationship of the predominantly younger Pagans to their traditions, parents and peers could be explored. Inescapably, though, the fact most are 'drawn to' or 'called to' the Paganisms suggests the growth of individual choice that characterises modernity. It seems also likely that the growth of female-centric faiths also has a relationship to the emancipation of women and feminist causes throughout the 20th and 21st Century. The contemporary Paganisms are temporally a recent phenomenon and the traits of modernity and/or postmodernity appear in them; they are actively chosen, the books and trappings can be marketed, sold and bought freely, many traditions borrow extensively from others, and movement between paths is often seen as part of the process. Howard Eilberg-Schwartz (1989) saw Paganism as a Post-Modern phenomenon, due to the Pagan's critique of traditional power structures (priestly hierarchies, formal services), rejection of reason's absolute priority (re-enchantment) and reconnection with nature. Purely anecdotally from personal experience, few Pagans consider their path to be the only correct approach to faith, but we currently lack the data to be certain. It would also be an

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error to assume that each particular Pagan path sits in the same sociological place, when each continues to change and evolve over time and space.

# 2.5 Concluding remarks

Although the nature of religion in the 21<sup>st</sup> century is strongly influenced by modernity, it remains a strong motivator of behaviour and an important part of many people's lives. Religion can be seen as a multidimensional concept, fundamentally to do with the identity and actions of human beings. The range of different religions can be understood as the beliefs, behaviours and moral guidelines through which adherents connect and interact with both the transcendent and the mundane; each religion has similarities and differences which manifest changes over time.

Religious worldviews typically reference a transcendental being or force (such as a deity), an understanding of how the world is in relation to that transcendent, building stories and rituals which reinforce that understanding and shape the moral rules related to those beliefs. Although specific religious beliefs vary extensively between religions, there are many commonalities. In this sense religions have a resemblance to each other, even if they are different in outlook. In particular, the presence of beliefs, behaviours, moral obligations and a *transcendent* within the Paganisms illustrates that, like the more well-known Abrahamic and 'Eastern' faiths, the Paganisms are religions. As such, they deserve some of the attention previously afforded to the others in the ethics literature.

It would be a mistake, however, to claim that *only* religious worldviews can be identity giving and morality giving. Worldviews reflect fundamental beliefs about reality and the obligations which arise from that reality or narrative. The intimate relationship of worldview type beliefs to our ethical reasons to accommodate beliefs is explored more in Chapter Four;

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ultimately Care Respect as the foundation for ethical accommodation works for religious belief and other kinds of worldview belief as well.

That Pagan worldviews are in many ways characteristically modern, does not detract from the fact that the Paganisms influence and shape beliefs, behaviour, and moral action at an individual level. This potentially impacts on healthcare decisions, as the next chapter explores, and informs the reasons we take the beliefs of patients seriously (chapter four *et seq*).

# 3. The impact of religious beliefs on healthcare

This chapter explores the issues that can arise when the religious beliefs of patients impact on their medical care. Although some ethical approaches are mentioned, it is not intended that the chapter should encompass those discussions as they form the basis of chapter four *et seq*.

In the UK, healthcare is normally provided within a secular environment and relies on modern, evidence-based approaches to treatment. However, the patient's worldview and experience often differ extensively from that of the professionals providing care, leading to conflicts over the relative importance of different aspects of that care. This interface between religious beliefs and healthcare creates a spectrum running from cases where the religious belief has a negative effect on health, to cases where religion is a positive benefit to patient wellbeing.

The classic example of refusal of a particular medical intervention -that of Jehovah's Witnesses and blood products- exists alongside cases where demand is placed on the provider for 'exceptional' life-prolonging treatment. Religious beliefs can also impose obligations that may be hard to meet in the hospital setting, such as regarding religious practices, particular clothing, diet, or interaction with other genders. These are events with daily impact. Importantly, patients may fear reactions to their religious beliefs, from ignorance to discrimination and bullying. These may be less dramatic examples of religious belief interacting with healthcare provision, however mishandling these has the potential to alienate patients from the organisation they are coming to for help.

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Although there is a need for healthcare ethics to address issues outside of the emergency and hospital environments, the thesis focuses on the emergency/hospital environment as an initial proving ground for the ethics of accommodation.

Using the nature of Paganism discussed in chapter two, and the experiences of patients with religious beliefs from the literature discussed in this chapter and elsewhere, I present three example scenarios. The ethically salient points of the cases (respect for autonomy and capacity, beneficence and harm, staff understanding and attitudes, plus resource allocation) give rise to the considerations in chapters five and six. The overall purpose of these scenarios is to illustrate an evaluation of ethical ways of accommodating religious beliefs in Chapters Seven and (particularly) Eight.

# 3.1 Religion's impacts on health care

Although religious adherence is declining in the UK (see section 2.1.4), for many people it is nevertheless deeply meaningful and has a profound effect on how they live their life. The literature on religion and healthcare often features scenarios from acute medicine and hospitals. However, Barrow insightfully remarks that:

the tendency of the acute sector to hog the lion's share of attention (and money) should not infect bioethics. Many patient's experiences are in nursing and social care homes, and there are far more problems for the ethicist than end of life dilemmas...' (Barrow 2003 p.140)

Thus, although the paradigm example is probably the refusal of blood by Jehovah's Witnesses, the majority of patient experiences (as was mine) are far less dramatic than this. It is not only the life-threatening which is an ethical consideration, but the treatment of folk

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in their homes, residential care, doctors' offices, and with chronic conditions. Both health and religion can pervade every aspect of life. However, developing an approach to the ethics of accommodating religious beliefs requires starting somewhere to develop the principles. Therefore, the remainder of the thesis focuses on the acute sector.

For anyone, a stay in hospital or a medical diagnosis can be disorientating and challenging even where the condition is not life threatening. A condition may impose new limitations on a person's capabilities at work, in the home and in their personal life, with the potential burdens of medication and treatment regimes, reduced incomes and radical loss of future plans. Managing these changes tests a patient's resilience and coping resources, and may force a change in beliefs about themselves, their identities and their abilities (Hale, Treharne et al. 2007, Exley, Letherby 2001, Charmaz 1995). It may lead to the patient moving unwillingly from a world<sup>32</sup> in which they understand the norms, to one with which they are completely unfamiliar. For a patient with strong beliefs, these are inevitably involved in their experience of illness (Astrow, Puchalski et al. 2001). For example, a significant number of NHS England inpatients between 2007 and 2008 (up to 27%), felt their beliefs were an issue in the healthcare environment, and for at least a proportion of these the needs were not met (Clayton 2010). Additionally, Trusts may neglect to question patients about the perceived satisfaction with this aspect of their care (Clayton 2010) and Healthcare Organisations sometimes do not adequately record patient beliefs and preferences about religious and spiritual care (Swift, Calcutawalla et al. 2007). In 2017, the Care Quality Commission's data indicates that many patients who reported religious affiliation had less than the mean level

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of satisfaction with emotional support, respect for their values, with food, and with being

<sup>&</sup>lt;sup>32</sup> I am using 'world' here in the sense expressed by Maria Lugones (Lugones 1987 pp.9-12), a 'world' being, at its most simple, a combination of outlook and physical reality.

treated with respect and dignity (Care Quality Commission 2018). Muslims and Christians often rated above the mean.

To help illustrate areas where healthcare and religion may come into conflict, I have split the impact of religious beliefs on treatment decisions into categories. The first is issues around life, including requests for prolongation of life and issues with abortion. The second is issues around death. The third is the nature of the body and what can or should be done with it, including refusal of care. The fourth relates to the mind and mental experiences, including religion and psychiatry. The final element is the religious person themselves, their relationship with themselves, the transcendent and other people.

## 3.2 Life

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Many religions, including Christianity and Islam, consider life to be sacred (Samra 2011). As such, decisions about life and death are sometimes seen as being in God's hands, rather than for humans to make.

# 3.2.1 Embryonic life

Those who believe in the sanctity of all human life, and who believe that life begins at or close to conception, may have difficulty with procedures such as termination of pregnancy, the use of embryos in research or treatment, and relatedly, of treatments for infertility or contraception (Department of Health 2009 pp.26-27). Those who oppose contraception consider embryonic cells involved as having life, either before they come together, or in the few cell stage. Hormonal and other contraceptives, or 'morning after pills' take or waste these lives. In general, patients who have these beliefs will not seek these treatments, (or may seek to access them clandestinely if there is a social pressure against them) although

they may sometimes attempt to prevent others accessing them, as can be seen by protests outside clinics where abortions are performed. Problems may arise when hormonal methods of contraception, such as the pill, are prescribed for non-contraceptive purposes, or if a treatment required to save the mother's life will also result in the death of the foetus.

Many of the challenges presented by contraception are also those presented by IVF technologies and embryo research. Some who may find contraception acceptable find the systematic production of 'surplus' embryos and their eventual loss or use in research as a step too far (Department of Health 2009 p.27).

## 3.2.2 Maintenance of life

Religious beliefs can also lead to requests for provision of treatment that is not medically indicated. Requests in advance by the patient, or at the time by the family, to maintain life support or for futile treatments are the clearest examples of this kind of difficulty. Here, the religious belief that life is in the hands of God, and that it should be maintained at all costs will not allow the withdrawal of medical treatment.

Orr and Genesen (1997) give the following example from their practice:

The three-and-a-half-year old daughter of a devout Muslim family who have lived in the US for several years has been unresponsive for two weeks from recurrence of a malignant spinal cord tumour for which there is no further treatment available. She also has severe, progressive Adult Respiratory Distress Syndrome. She is in the paediatric intensive care unit (ICU) on multiple organ support, and her primary physician, paediatric intensivist and consulting specialists have all asked the father to allow withdrawal of her current level of life-support. He demands that all

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measures continue because "Only Allah can take a life" and he understands his role as her father is to continue all efforts to sustain her biological life. (Orr, Genesen 1997 p.143)

Orr and Genesen suggest that the trust and wellbeing of the family are real and meaningful concerns for medical practice. However, highly intensive support is expensive and may be in short supply. In addition to the concern that such treatments are not working or becoming burdensome to the patient, the equipment and facilities may be needed to treat someone else who would potentially benefit- a situation considered by Savulescu (1998b p.383) as unacceptable discrimination against atheists.

#### 3.2.3 Birth

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The arrival of a baby engenders changes in personal beliefs and capabilities, albeit one that is usually (but not always) joyful. The purpose and meaning of birth, the changes expected in behaviour from the parents – in particular the mother. The ways in which the arrival of the new-born are marked are also within the remit of religion. Rituals govern the induction of the baby into the community; circumcision, baptism, naming. The process of birth itself may also be something which a religious belief might shape, for example 'quiet birth' in Scientology (Church of Scientology International 2014), a preference for a 'natural', non-medicalised childbirth -which might be found within Paganism (Whedon 2011)- or reluctance to take pain relieving medication due to biblical punishment of Eve's sin (Miller, Shriver 2012 p.713).

It is perhaps particularly tragic that both ends of life can be very close together. The birth of a baby that is soon to die stimulates conflicting and difficult scenarios; it may be important for the religious needs of birth to be completed before those of death to ensure safe passage

for the infant and emotional release for the parents. Ethno-cultural and religious beliefs can be especially important during this time:

[T]he mother's philosophical principles and global experiences, such as ethnocultural background and level of religious observance, had a more profound influence on her medical ethical decision-making than did specific past personal experiences, such as infertility problems and/or previous children with serious physical or mental disability (Hammerman, Kornbluth et al. 1997 p.169)

## 3.3 Death and disease

When a condition is terminal, not only must the patient, their family and carers adjust to the limitations posed by the condition, they must also adjust to the sometimes-rapid approach of their own death. Modern medicine may be able to alleviate some of the pain and other physical symptoms, but the patient's physical recovery is no longer a possibility. Death represents a significant (and often fearful) transition in people's existence – both that of their own life and that of others around them. It is perhaps unsurprising that the nature and purpose of death (e.g. release from corporeal life, a natural part of a cycle, punishment for sin), the continuance of the self (e.g reincarnation, heaven or hell, ascent to higher existence, none) and the appropriate ways of managing and responding to death are all components of religious (and non-religious) belief (Dawson, J. 2011a).

At the end of life then, perhaps more than any other time, the values of the patient, including their religious values, take on an even more significant role (Guinn 2006 pp.348-349) particularly given medical cure is no longer possible (Hill, Patrick 1996 p.203). Patients confirm that spirituality and meaningfulness, life review, conflict resolution, and

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relationships matter at this time (Steinhauser, Clipp et al. 2000 p.185). Religious prayer or ritual that joins in worship, affirming shared views and sense of purpose helps to bring closure (Lo, Kates et al. 2003 p.412).

Preparation for the impending death and treatment after death may be governed by ritual and religious requirements varying between religions (Dawson, J. 2011b, Samra 2011, Guinn 2006). These rituals and practices can relate to things intended to support the patient throughout the dying process such as prayer, or relate to the definition of death and the treatment of the body after death. Failing to properly account for the patient's (and their family's) cultural and religious needs and understandings of death is to leave them isolated, afraid and harmed (Johnstone 2012 pp.183,186).

### 3.3.1 Palliative and End of life care

There is a sense for many religions that the patient needs to reconcile themselves with their life and their creator during the dying process (Samra 2011, Dawson, John B. 2011b); patients who perceive themselves to have done bad things might be concerned that failure to atone will impact on their afterlife. Thus, as an example, a Roman Catholic patient might require the attendance of a priest to administer last rights or hear confession.

A religious belief might also prompt someone to adopt a particular manner of dying, such as the practice of *Sallekhana* – fasting to death - among Jains (Samra 2011 p. 27, Braun 2008); or a preferred location for dying such as Hindus who prefer to die at home (Sulmasy 2009 p.1638, Samra 2011). For some, such as some Buddhists, it is important to remain as conscious as possible until the last moment to enable prayer or contemplation (Samra 2011 pp.18), affecting decisions around sedating medication (Department of Health 2009 p.30).

Religions can allow for the removal (or non-commencement) of treatment when that treatment is no longer of any benefit to the patient. Paradigmatically, this might be the removal of intensive life support measures or Do Not Resuscitate (DNR) orders. However, it may also include artificial nutrition and hydration that replaces the patient's lost capability to eat and drink. Since the Bland case (*Bland*, AC 789 [1993]) artificial feeding can be classed as treatment. Religious objections can therefore be raised to the withdrawal of artificial hydration or nutrition. In one example, Jews may object to the withdrawal of tube feeding in a patient near the end of life (Gillick 2001 p.1268) on the basis that this does not constitute medical treatment but instead, the most basic care one can give.

Several studies show that the religious belief of the attending professional impacts on the kind of care they give and the way they approach ethics – for example at the end of life (Lawrence, Curlin 2009, Seale 2009). Those who have strong religious views may demonstrate greater reluctance to prescribe high doses of pain-reliving medication to dying patients, on the basis to do so is to hasten death (Curlin, Nwodim et al. 2008). It is therefore not only the patient's beliefs that can impact on the dying process, but those of their carers'.

## 3.3.2 Definition of the moment of death & organ donation

The precise moment at which a patient is determined to be dead has ramifications for the withdrawal of life support in intensive care, and for the point at which it is permitted to remove organs. The standard method for diagnosis of death is the use of Brain (Stem) Death – the irreversible cessation of breathing combined with the irreversible cessation of brain activity. Some followers of Judaism object to this definition, as for them death only occurs when the heart stops functioning (Gillick 2001 pp.1269-1270). Although the majority of Jews do not object to the donation of organs per se (as it is permitted to set aside most moral

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laws to save a life – the principle of *pikuach nefesh*) they believe to do so on a brain-death criterion is to remove organs from someone who is not yet dead. This places a moral burden on both those who wish to give their organs after death, and on those who could benefit from receiving such a transplant.

#### 3.3.3 Treatment of the dead

Aside from the moment of death and the use of the deceased's organs, different religions have different regulations about what may be done to the body after death. This may include the acceptability of a post-mortem examination or autopsy, the acceptable period between death and burial, and the gender of those tending to the body.

Hindus, for example, might consider that an autopsy will "disturb the still aware soul that has just separated from the body" and should be avoided (Sulmasy 2009 p.1637). A soul that is disturbed in such a way may become trapped, unable to move on leading to torment for the soul and anxiety for the family. Hindus will accept the need for such procedures if requested by law but may be reluctant otherwise. Also, in Hinduism, it is considered important that the son of the deceased is given the opportunity to lay out and clean the body (Samra 2011 p.23).

Muslims may hold that that the deceased should be cleaned and laid out by someone of the same sex or a family member, must be wrapped in a particular way, faced toward Mecca, and not be autopsied unless required by law (Samra 2011 p.26).<sup>33</sup>

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<sup>&</sup>lt;sup>33</sup> http://www.mcb.org.uk/downloads/Death-Bereavement.pdf- a talk given by Imam Dr Abduljalil Sajid to St Christopher's hospice. Website has since been redesigned and this no longer exists.

## 3.3.4 The body after death

Some religions, at either a large or individual scale, believe the body should be left entire and unmutilated, to secure the afterlife. Some fundamentalist Muslims hold this belief about amputation (Kirkup 2007 p.97) and other Muslims may want to retain the amputated limb for burial with themselves later (Kirkup 2007 p.104). Some Jews may also seek such preservation of their organs, leading in one case to a lawsuit when the amputated limb was cremated by the hospital (JTA 2014). Such a belief might also prevent an individual from giving up organs on their death (or before death, if a kidney transplant is proposed) or prevent post-mortems being carried out (Burton, Collins 2012).

# 3.4 Religious beliefs and the nature of the body

Many religious strictures consider that some substances should not enter the body, because if they do, the soul or essence of the believer becomes tainted in some way. This can make the achievement of salvation or enlightenment more difficult or impossible. The patient may be bound by their religious duty to refuse treatments including those substances, even if the consequences of refusal appear to us as negative ones. Ensuring access to continued spiritual life after death, such as access to heaven, also prompts many religions to have beliefs about the proper treatment of the body, during life and after death.

#### 3.4.1 Blood transfusions

The refusal of Jehovah's Witnesses to accept blood products on the basis of decisions of the governing Watch Tower Society is the paradigm case of treatment refusal on the basis of religious beliefs. The Jehovah's Witnesses' refusal originates in a biblical requirement to

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abstain from blood (Ridley 1999 p.469) and can also extend to beliefs about the acceptability of organ transplantation.

Miller (1981) in his discussion of autonomy and refusal gives the following example of a Jehovahs witness refusal of blood products:

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A forty-three-year-old man was admitted to the hospital with injuries and internal bleeding caused when a tree fell on him. He needed whole blood for a transfusion but refused to give the necessary consent. His wife also refused. (Miller, 1981 p.22).

The judge requested by the hospital recognises some key areas of concern: is the patient being coerced? Is the patient's judgement clouded by medication or have they failed to grasp the situation?

She asked him whether he believed that he would be deprived of the opportunity for "everlasting life" if transfusion were ordered by the court. His response was, "Yes. In other words, it is between me and Jehovah; not the courts... I'm willing to take my chances. My faith is that strong... I wish to live, but not with blood transfusions. Now get that straight." (Miller 1981 p.22)

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Although some Jehovah's witnesses hold to this policy, there are many within the community who do not and campaign for revision (Elder 2000 pp.375-380). This is illustrative that even within one particular umbrella, there are numerous subdivisions, and within each of those there may be different opinions and traditions that lead to a refusal (or not-refusal) of a particular treatment option.

## 3.4.2 Other biological material and alcohol

Some substances might be prohibited by under the religious rules followed by the patient. Key examples are the rejection of: gelatin-containing medications, vaccines made with egg, alcohol-containing preparations, other animal derived treatments such as heart valves; and the potential rejection of embryonic stem-cell derived treatments (Vegan Society 2018, Tatham, Patel 2014). Many of the animal derived sources in medications are not the active ingredients, being colourings like cochineal or used to make capsules such as gelatin, but in the cases of some hormonal and antibody treatments the active treatment itself comes from an animal source (Syan 2013, Greater Glasgow and Clyde NHS 2016, Poku, Dezelak et al. 2012). This might include skin substitutes, (Enoch, Shaaban et al. 2005) or porcine heparin (Newson 2010). Those with secular beliefs about animal rights and who therefore practice vegetarianism or veganism, may also want to abstain from animal derived products. In cases where there are no alternatives to these products, the patient must choose whether to violate their deeply held beliefs or risk further illness or death.

Enoch & Shaaban's study (2005) highlights the use of skin substitutes and dressings that may contain animal products, by asking representatives of several faiths what was acceptable. Islamic leaders suggested biological products were acceptable, except those from pigs. Alternatives should be used even if the healing or treatment took longer, but an exception might be made if there was genuinely no alternative. Chinese representatives reported that cow derived products were unacceptable to some Hindus and Buddhists. Foetally derived products (if they were to be available in future) might also be unacceptable as reported by a canon of the Anglican Church, and those derived from neonatal prepuce were unacceptable to Quakers (Enoch, Shaaban et al. 2005 pp.3-4). The religious leaders

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consulted thought that the consent of the patient was essential and that it is necessary to tell a patient about the contents of their medication in order for there to be valid consent.

Newson (2010) sought ethics guidance regarding a patient at risk of blood clots following an operation, and whether he should be told of the porcine components in the prophylactic heparin (Newson 2010 p.5). It was argued that a) the ingredients should be disclosed on the basis of allowing the patient to make an informed choice - indeed, this was something that should apply to all patients (Newson 2010 p.10), and b) that although there are often doctrines of necessity within religions that permit use of usually forbidden substances, prophylactic use was unlikely to cover that situation (Newson 2010 p.11).

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In the case discussed by Newson, the Doctor had identified that the ingredients of the medicine had animal derivatives. Enoch and Shaban noted that such knowledge was poor among health practitioners, and not always available even when asked for (Enoch, Shaaban et al. 2005 p.3-5). This issue was raised by Tatham and Patel (2014) who surveyed the biological contents of the 100 most commonly prescribed drugs in primary care. Of these, 73 contained one or more of lactose, gelatine, or (potentially animal derived) magnesium stearate. However, information on the origins of the contents was difficult to obtain, unclear, inconsistently reported, and sometimes incorrect. Problems with the contents of medicine may adversely affect adherence to treatment (Tatham, Patel 2014) but providing alternatives will have cost implications as they are often more expensive (Newson 2010 p.10). Religions, such as Islam in Newson's example, often recognise a specific virtue of caring for the sick and an obligation to preserving life. Prohibitions on what may be eaten can be interpreted as not applying to substances taken intravenously. They may be allowed if death would result from abstention- although there may be a need for official religious exemptions to be given by a religious leader. As an example, regarding porcine heparin, Newson writes:

Islam also includes five key legal principles, of which one is that 'necessity permits the impermissible'. To this end, if there is absolute necessity that a particular treatment course be followed, and there are no religiously lawful alternatives, the above Sacred Laws may be temporarily suspended. Such a suspension would usually occur following a discussion with a religious leader (Newson 2010 p.8).

1990 However, even within this situation there are some sects who do not accept the possibility of a relaxing of the moral rules regarding one's own intake, or this may also be the case for an individual believer (Albar 2007, McMahon-Parkes 2013, Erbay, Alan et al. 2010).

## 3.4.3 Unusual treatments & practices

Often, a refusal of a certain kind of medication or treatment leads to a need for a certain type of replacement. As outlined above, because the contents of some medications, there may be cost and health implications to providing these replacements. Some patients may request (or turn down standard treatment in favour of) alternative therapies (Votova, Wister 2007, Multiple Sclerosis Trust (No date)) - although there does not seem to be a clear *religious* motivation behind many of these requests. Some alternative therapies may be useful as adjuncts to medical treatment or offer comfort if nothing more can be done, however the evidence base states that treatments such as homeopathy have no active effects (NHS Choices 2015c). There may also be clear evidence of harmfulness or problems with interactions between medications -such as that that exists between St John's Wort and SSRIs (Rull 2011).

## 3.4.4 Changing the body

Relatedly, as it also involves an 'unnatural' change to the body, there is also the Sikh prohibition on the removal of hair. Uncut hair represents adopting a simple life, reduces unwholesome pride in the appearance and symbolises moving beyond concerns of the body towards spiritual maturity (BBC 2009) – so reluctance or refusal to have it removed may make some procedures difficult (Dawson, John B. 2011a p.16), or lead others to reject cosmetic treatment, such as those Sikh women who do not shave despite suffering hirsuitism. For some Jews, also, cosmetic procedures may present a problem (Davidson 2012).

#### 3.4.5 Circumcision

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As well as requests for alternative medications, there may be requests for procedures that are not clinically indicated but are required by the patient's religion or cultural background-such as circumcision of boys requested by Muslim and Jewish families (Dawson, J. 2011a p.160, Dawson, J. 2011b p.140), or 'female circumcision' (Hellsten 2001 p.248–253) practiced by some African communities and termed Female Genital Mutilation (FGM) by its opponents. FGM is classed as abuse in the UK.

This raises the question of how religiously influenced treatment decisions should be made for others, particularly minors. I will not consider in depth the issues around the treatment of minors, although taking decisions for others is explored more in the section on autonomy in chapter five. However, an adult convert to a religion that requires circumcision might also find themselves in the position of having to undergo it, a process that arguably should involve trained professionals; however, those involved would have to decide if invasive

procedures with no medical indication are acceptable practice in the light of other values of medicine such as avoiding harm.

# 3.5 Religious belief and mental health

When a patient acts in a way that does not seem to fit perceived normal beliefs or behaviours, they may be considered as lacking capacity or as mentally ill; resulting in a psychiatric consultation to evaluate their competency to make a decision. However, the reason behind their 'not-fitting' might be due to a genuine mental illness, to their religious beliefs, their personality or to a combination. Patients, therefore, may fear they will be criticised or detained because their beliefs differ from the norm, limiting the effectiveness of their care.

A key tension regarding the *rationality* of religious beliefs is raised by Beauchamp and Childress. Their example of a man called Ray who takes a literal interpretation of 'if thine eye offends thee, pluck it out' (Beauchamp, Childress 2009 p.117, Martin 2007) illustrates the difficulty of telling rational from irrational. It can also be challenging for psychiatrist and patient alike to interpret what are religious experiences and states and what are harmful effects of mental conditions (Dein 2013 p.1).

Religion's effects on mental health can be both positive and/or negative, depending on the condition and also on the faith group of the patient (Dein 2013 p.1) thus The Royal College of Psychiatry's guidance on religion recognises that religion can affect numerous aspects of mental health care (Cook 2013 p.5). Handling the spiritual and religious dimension of the patient's care sensitively and empathically affects the patient doctor relationship positively (Cook 2013 p.6).

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## 3.5.1 Symptomatic or spiritual?

The difficulty in diagnosis at the intersection of religion and mental health is largely understandable. Aspects of religious belief and experience (hearing God, seeing angels, a sense of being connected to a deity or disconnected from the self) have substantial overlap with auditory and visual hallucinations - they might appear indistinguishable from schizophrenic or psychotic symptoms (DeLisi 2009 p.17) or from sensory disturbance in conditions such as epilepsy. Another staple concept in psychology is the concept of 'magical thinking' where external consequences are considered to happen or be deserved because of a person's thoughts (Matsumoto 2009 p.294). An example might be a child who associates their anger at a parent with that parent's subsequent death, or someone in desperate circumstances believing that their bad luck is some kind of punishment for a fault of the individual. This type of thinking is generally considered 'unhelpful' in therapy. However, the belief in the ability to influence things by non-mundane means underpins a lot of religious belief such as efficacy of prayer, karma, magical spells, channelling energy or the presence of some kind of divine plan. In a similar vein, dissociation and mood swings might be interpreted by the psychiatrist as a mental health condition, or by a shaman as the consequence of tangling with the otherworld.

The confusion is not limited to the symptoms of mental health conditions such as hallucinations. Patients who perform practices that could be seen as self-harming – for example, cutting to produce blood for a ritual or to produce scars depicting important rites of passage may be assumed to be suicidal, making 'cries for help' or suffering from psychological disturbance (Hathaway 2006).

There are also religious practices which may be considered to be deliberate attempts to consider or ameliorate mental (or physical) conditions as though they were spiritual

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problems. Problems may be seen as spiritual dysfunction, leading to either a delay in seeking or a refusal of conventional treatment. Religious patients with mental illness may interpret their illness as a punishment, therefore as being undeserving of treatment, or may rely on prayer to cure the illness (Pandarakalam 2007 p.2), or interpret it as demonic possession (Department of Health 2009 pp.32-33). For example, some religions, such as branches of Evangelical Christianity, believe mental illnesses are curable by prayer and bible study alone (Holpuch 2014) and the Christian Scientists may reject or neglect modern medicine as they believe that illness results from spiritual causes (Samra 2011 p.39). Meanwhile, secularised practices derived from Hindu and Buddhist teachings, such as Mindfulness and meditation, are common elements of modern psychotherapy (Baer 2003, Hirst 2003).

In general, contemporary psychiatry tries to draw the distinctions between things that make sense within the community context and patient's background (prayers, religious belief and religious experience) and those that have arisen outside of this (Pandarakalam 2007 p.2). However, extreme extensions of the community belief can cause difficulties (obsessive washing or praying, as opposed to the regular religious requirements, for example (Cosgrove 2011)), so the general distinction is that treatment is required when the patient's experiences become harmful and affect their wellbeing and functionality. If the patient feels God is forgiving they will do better than a patient who believes God is punishing (Dein 2013 (after Pargament) p.2).

Concerns about the way in which their religious beliefs and behaviours might be judged by their carers can impact on the willingness of patients to talk about their beliefs both in general and in psychiatric care. In Hathaway's cases, the patients were placed at a disadvantage by their fears around expressing religious sentiments. Anecdotal reports of

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situations arising through mental health (in this case Pagan) can be found in blogs and communities, and in discussions. For example, a Pagan therapist writes:

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I had one client who claimed her antipsychotic medication was increased, with no conversation, simply upon her mentioning that she "talked with the Goddess". ... I have to wonder how lack of respect and knowledge effects the treatment of countless Pagan clients in little ways that we may never even know about (Reeder 2013).

Kimberly Kirner, who is working on a Pagan Health survey in the US, reports concerns held by Pagans in particular about their mental health experiences to Patheos Pagan:

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I rather expected, but was still saddened to find, that Pagans particularly feel misunderstood and underserved in the area of mental health. Because that aspect of health is so culturally constructed, it is natural that Pagans would be worried that their spiritual experiences or practices might be mistaken by a mental health professional for mental illness, but it is still unfortunate (Miller, T. 2011).

In another Pagan example, Hathaway (2006) discusses cases referred to a Military clinic in the US. The cases include a Wiccan Staff Sergeant with depression (Hathaway 2006 pp.248-250), and an Odinist PFC, referred as potentially unfit for service after cutting himself on duty.<sup>34</sup> Both had been afraid to disclose their beliefs for fear of reprisal and judgement. Overall, Hathaway suggests that having a non-judgemental understanding of different

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<sup>&</sup>lt;sup>34</sup> PFC Jones' cutting had been due to his interpretation of a religious warning against unsheathing a knife without drawing blood (Hathaway 2006 pp.252-253).

beliefs is useful to those working in psychological fields, as it assists in discriminating between religious experience and psychosis, and leads to better patient interaction (Hathaway 2006 p.256).

## 3.5.2 The impact of religious beliefs on mental health

There have been a number of studies into the relationship between religiosity /spirituality and mental health. In a systematic review in 2010 (Bonelli & Koenig 2013) Bonelli and Koenig determined that there are both positive and negative correlations between patient spirituality and their mental health conditions (Bonelli, Koenig 2013 p.658). The situation was complicated by the differences in measurements of spirituality/religiosity, which has implications for the structuring and validation of studies exploring the relationship between religion and health (Bonelli, Koenig 2013 p.670, Cosgrove 2011 p.5). There is evidence that the positive and negative associations relate to different mental health conditions - such as depression, addiction and suicide being ameliorated by religious behaviours and beliefs but schizophrenia showing a mixed result and bipolar showing a mixed/negative result (Bonelli, Koenig 2013 p.669). For some patients, though, the promise of a 'better' afterlife may inhibit their resistance to suicide, or religious beliefs may create guilt and fear (Pandarakalam 2007 p.3). Studying OCD, Cosgrove observed that different religions might have different effects, different definitions of religiousness (Cosgrove 2011 p.6-7) and necessitate different treatment strategies (Cosgrove 2011 p.8) based on the importance of religious behaviour to the patient. The patient's attitude to their condition and their compliance with medication and treatment, plus the attitudes of others in the community (Borras, Mohr et al. 2007) will all be shaped by religious considerations.

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# 3.6 Relationships with the divine and the other

#### 3.6.1 Gender

Due to the gender rules governing physical contact and exposure of body parts, requests may be made for treatment of patients by health professionals of the patient's gender. Women, in particular, may require female health professionals. This is not necessarily due to religious concerns, as women from many backgrounds can feel uncomfortable around male HCPs and especially around intimate examinations from a male, for a variety of reasons. Particularly, however, devout Hindu, Jewish, Muslim and other women may request female care (Samra 2011 p.29). Religious groups such as extremely orthodox Jews may also request care from males for their male members (Samra 2011 p.29). This can present problems for service provision, as appropriately qualified staff of a particular gender may not be available, particularly in an emergency situation, but the patient's convictions may be so intense that treatment from the non-preferred gender is rejected.

#### 3.6.2 Behaviour

As well as requests for treatment of the individual, there may also be requests for non-medical and non-scientific actions to be performed with the patient, at home, on the ward or in the patient's hospital room. Such requests could include family congregations (Buryska 2001 p.118), and anything from prayer and ritual at the bedside, through to the (albeit exceptional) sacrifice of animals (Burton, Bosek 2000 p.101). In Burton and Bozek's example, some are concerned these practices present medical risks (such as the introduction of bacteria) or cause distress to other patients, visitors and staff. Others may feel that this reflects an unjustifiably poor attitude towards people who follow 'primitive' religions and are therefore 'primitive' in their thinking (Burton, Bosek 2000 p.102). For Burton and Bosek, 101

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the consequence of assuming certain things about the reasoning skills of people on the basis of their religion is deeply problematic, although they recognise the legitimacy of concerns about infection and disturbance.

There may also be concerns about hygiene raised by religious icons or habits. As an example, the religious practice of rubbing the doorway mezuzah in Jewish homes (and hospitals) might present a risk of infections passing from person to person (Youngster, Berkovitch et al. 2009) if not disinfected regularly.

## 3.6.3 Punishments and Exceptionalism

It is possible that a belief in divine punishment may lead some patients to believe that their illness is a deserved punishment for a previous transgression Sulmasy (2009 p.1636) suggests a scenario in which a patient with uterine cancer believes it is punishment from God for an earlier abortion. Borras et al. (2007 p. 1242) report a patient who views their schizophrenia as a punishment. A patient who believes they are being punished may be reluctant to seek treatment and it may affect their adherence to or choice of treatment.

Sometimes, a patient or representative may refuse treatment not on the basis that their religion prohibits the treatment, but because the patient is, because of their belief, going to be saved without it (Martin 2007 p. 36, Orr, Genesen 1997 p.144). Such cases can be troublesome, because in the standard refusal case, the patient usually appears fully cognisant of the consequences of refusal, whereas in this scenario they do not so appear. The patient also seems to be making a claim that they have a particular exceptional relationship with their deity. A refusal to accept the evidence in favour of the treatment, or to recognise the likely negative outcomes of the refusal, is a challenge to autonomy accounts of accommodating religious belief and is discussed in more detail in chapter five.

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### 3.6.4 Religious ignorance, prejudice, bullying and discrimination

People have pre-conceived attitudes about cultural and religious beliefs, ranging from complete ignorance to the factually incorrect to the actively hostile. The Woolf institute independent report (Butler-Sloss 2015) noted there are, for example, significant problems with the way discourses about religion appear in the media, illustrated by 'The Representation of Islam in the British Press' (Baker 2013), and poor 'religious literacy' that contributes to ignorance and hostility. In light of this, it can be difficult for people to be aware of, or see, harms they may themselves be inflicting on those who are different to them. Members of faith groups are susceptible to prejudices and misunderstandings. This in turn may impact on how prepared they are to make public their beliefs (Hamilton, Levine 2006, Smith-Stoner, Young 2007 p.280) with knock on effects for disclosure to health professionals, but also for how well the patient responds to treatment or manages in a healthcare environment (House 2002). Bullying and discrimination, in and of themselves, can have profoundly negative effects on wellbeing (Royal College of Psychiatrists 2008), affecting both patients and staff.

Prejudice may arise because of historical attitudes between religions, towards certain races, or from those with no religion at all. Members of the Jewish and Islamic faith report blatant direct acts of intimidation. Pagans face ridicule and suspicion about their beliefs (particularly that they are Satanists (Smith-Stoner, Young 2007 p.281, Anonymous Luciferian, Anonymous Witch 2019, *personal communication*) or abusers (see chapter 1)).

The participant recounted a story where a hospital chaplain, upon discovering that a patient was Pagan, declined to offer assistance to the patient and family, even refusing to locate Pagan clergy. (Tejeda 2014 p.96)

Tejeda, in exploring Pagans' experiences and fears of being discriminated against recounts:

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Religious believers of all kinds may be targeted (or belittled) for having non-secular, non-scientific, (therefore 'delusional') beliefs about 'non-existent' Gods, regardless of their professional or personal achievements.

For some the ability to mock and/or challenge religion is an aspect of freedom of speech and a legitimate method of criticism over damaging behaviours such as killing and abuse (British Broadcasting Corporation 2013b), but the line between what is intellectual rigour and being cruel or bullying towards individuals is a difficult one. The UK has legislation against hate speech (e.g. *Racial and Religious Hatred Act 2006.*, *Public Order Act.* 1986), but it is slow to change entrenched moral attitudes and must walk the difficult line between differing faith imperatives. For some, 'religion is like stamp collecting or playing squash, a minor hobby' (Knott 1986 p.4) and therefore it is hard for those who view it in that way to see why anyone would care so much about it.

In healthcare, lack of understanding of religious beliefs, and the mocking of beliefs (or those who hold them) might be reasonably expected not to occur, given the focus on patient needs and lack of judgement. However, jokes and casual derogatory comments about various minorities are reported, for example one Pagan was prompted to start an online petition after being 'subjected to verbal intolerance and taunting by some members of staff who encouraged patients to join in, been [sic] likened to as a Satanist and weird and also told we sacrifice animals' while in hospital (Barfoot 2015). In an example of lack of knowledge, a Sikh wearing a *kirpan* was refused treatment because they were 'carrying a weapon' (Equalities

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<sup>&</sup>lt;sup>35</sup> On the matter of whether the truth is always a legitimate challenge, consider if it feels 'fair' to inform a mother who has recently given birth of childhood mortality statistics, to discuss divorce statistics in a wedding service or tell a grieving man the process of his partner's decomposition. There may be objective (or fairly objective truths) here, but there are still insensitive, bullying and unhelpful ways of raising them.

in Health 2014), and accusations and tribunals can result from (perceived) harassment on matters of faith of colleagues (Daily Telegraph 2015) or patients (Alderson 2009, British Humanist Association 2011, Dyer 2015). These cases illustrate the difficulties presented by ignorance of religious needs, identifying respecting and not discriminating against different beliefs, and the differences between discussing beliefs (at the patient's request or to facilitate meeting their needs), and the imposition of beliefs on another person. Even where there is no discrimination by the practitioner, patients may perceive there is, as one patient reports: "in my heart I feel these doctors, nurses or General Practitioners might think I believe [in

terrorism] just because I am a Muslim" (Mir, Sheikh 2010 p.335).

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However, the issue of prejudice and discrimination does not only show itself through discrimination against religion. There is another way that religious beliefs can have an impact, which is the refusal to accept care not because the care itself is contra-indicated by the patient's faith, but where the practitioner is in violation of something within the patient's beliefs, such as being homosexual or of a particular gender. For someone whose religious beliefs are part of a worldview in which certain classes of people (for example, of a lower caste, of a different gender, of non-heterosexuality) are seen as impure, unclean or unholy, being treated by one or sharing a room with one can present a problem. At one end of the scale, patients and visitors may be derogatory - openly and/or violently - towards staff, other patients and visitors (not necessarily because of their religious beliefs). At the other, it may be a more polite request. This presents particular difficulties for practitioners and institutions who are committed to the welfare of the objecting patient, but also to ethical values of non-discrimination, the welfare of other patients who may be affected, and the impact on the professional (Deacon 2011, Vydelingum 2006, Shaha 1998, Moghal 2014). Many NHS premises have 'zero-tolerance' policies against abusive behaviour, and prosecute

accordingly, but may tolerate such behaviour from a frightened and vulnerable person, particularly if their mental state is affected by psychosis, hypoglycaemia or fever, because they are not held fully responsible. The concept of toleration, and the limits placed on it, are discussed in more depth in chapter six, because if there are limits on the things that can be accepted, this will impact on the ethical treatment of religious beliefs.

Staff may also be reluctant to engage patients in discussion of religious beliefs due to concerns about proselytizing (Royal College of Psychiatrists 2013), feeling inadequate to the task (Morgan, A. 2017), or considering religious beliefs to be an obstacle to good medicine (Grol-Prokopczyk 2013).

#### 3.6.5 Staff

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The thesis is intended to focus on the position of patients, so the coverage here is intentionally brief.

Many religions mandate certain items of clothing or ritual actions that are at odds with the health service's standard procedures. As the working population of the UK becomes more multi-cultural, more practitioners potentially face the dilemmas of religious versus professional obligations. There are numerous potential examples, for example wearing of veils that cover the face is not permitted for NHS staff, as face to face contact is recommended for ease of communication between patient and practitioner; the requirement of modesty for certain types of dress can conflict with the bare below the elbows policy; religious items such as necklaces, bangles, scarves and turbans could represent a hazard or offend a patient; and requirements for prayer, holy days or fasting could affect staff levels and effectiveness. The NHS aims to strike a balance between

respecting the religious beliefs of staff and the clinical demands of practice, as seen in the 'Religion or Belief' (Department of Health 2009) document.

#### 3.6.5.1 Chaplains

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A hospital Chaplain is a salaried NHS employee who offers 'a service of spiritual care to all patients, their carers, friends and family as well as the staff of the NHS' (NHS Careers 2015). As such they are the 'face' of spiritual and religious care within the NHS. Chaplains are most often from Christian denominations (Sheikh, Gatrad et al. 2004 p.95) but there are increasing numbers of Chaplains of other faiths, and calls (particularly from secular and humanist groups), to provide pastoral support on a non-religious or secular basis. Chaplains may also be supported in their work by volunteer members of local faith communities (Swift 2015 p.7).

Although religious (and pastoral) care is often associated with chaplains, some people believe that the provision of chaplains should not be part of the NHS remit, given the tight demands of money. For example, in 2009 the National Secular Society suggested that "religious groups should fund their own presence in UK hospitals and save the NHS some £40m per year" (British Broadcasting Corporation 2009). NSS president Terry Sanderson stated that the £40m<sup>36</sup> figure was equivalent to employing 1,300 nurses or 2,645 cleaners.

"I think if people were given the choice they would choose the latter [nurses or cleaners] because frontline services are under pressure, they are going to be increasingly so as the recession bites, and it's important that

 $<sup>^{36}</sup>$  More recent figures place this amount at £29 million (National Secular Society 2015)

savings are made wherever they can be," he said (British Broadcasting Corporation 2009).

The counterpoint is presented in an article by Andrew Brown in the Guardian who wrote;

Chaplains are not there to substitute for doctors. They are there to help carry the burden of wretchedness, which is an unavoidable part of dealing with the dying. They are there to give hope to the staff that their work matters as much as to give hope to patients... (Brown 2009).

The responsibilities and standards for NHS Chaplains are covered by a Chaplaincy guidance document (Swift 2015).<sup>37</sup> The role of nurses in supporting a patient's spiritual and pastoral needs is also noted, highlighting that religious and spiritual needs are not solely the responsibility of chaplains. However, as religious chaplains are still required to meet the needs of their sponsoring organisation, the National Secular society continues to be unhappy with the NHS expenditure on religion.

## 3.6.6 Conscientious objection (CO)

Problems can arise through the desire of health care professionals, in particular doctors but also pharmacists and nurses, to remain true to the tenets of their faith by not performing actions contrary to their religious teachings. The classic example of CO in healthcare is

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<sup>&</sup>lt;sup>37</sup> In the 2003 version of the document, references to religion were to the nine major world faiths: Bahá'í, Buddhism, Christianity, Hinduism, Jainism, Judaism, Islam, Sikhism and Zoroastrianism. In the 2015 document, references reflect that religion refers to any religion (Swift 2015 p.6), but one of the crucial contributors, the 'Healthcare Chaplaincy Faith and Belief Group (HCFBG)' includes 'all 9 world Faith groups and the British Humanist Association attend as observers'. I note that there are fewer Jains and Zorastrians in the UK than Pagans.

objection to performing abortions, which first arose when abortion was decriminalised in most of the UK (*The Abortion Act 1967.*).

Authors such as Savulescu, suggest that when faith and (legal) medicine conflict, faith should take second place; those with a faith that prevents them participating in all of the acts sanctioned by lawful medicine should not be doctors (Savulescu 2006 p.294), or at least, remain in areas far distant from conflicting moral values. Reasons for a rejection of conscientious objection clauses are that it inconveniences and delays patients from seeking what they are legally entitled to (Savulescu 2006 p.295), and the obligation and duty of health care professionals is to meet the health needs of the patient first and foremost, as suggested in their guidance (Nursing and Midwifery Council 2015, General Medical Council 2009, General Pharmaceutical Council 2012 p.8). Concerns are also raised that allowing CO over issues of foetal life will allow professionals to claim exemptions from treating homosexuals, blacks, or women, according to their moral beliefs. However, the key difference is that respect for human life is a value of medicine, whereas discrimination and judgement against others is not. Gerrard indicates that "objection pertains to the act requested, not to the individual requesting it, and is acceptable on such grounds only" (Gerrard 2009 p.599) thereby preventing the concept being applied to types of people. Both Gerrard and Wicclair support CO, because medicine is a 'moral enterprise' (Wicclair 2000 p.215) in which integrity is crucial. People are drawn to practice medicine by the same core, life-focused values as prompt CO (Gerrard 2009 p.600).

Moral integrity can be understood by the statement "I could not live with myself if I did that" (Magelssen 2012 p.18). Integrity may lead practitioners to do morally admirable things, such as 'whistleblow' on dangerous or inhumane scenarios, even when faced with considerable pressure to do otherwise (Edgar, Pattison 2011 p.95). Although conscience and

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moral integrity is no guarantee of a good outcome (Deans 2011 p.4) or may lead to arrogance (Edgar, Pattison 2011 p.5); slavish identification with currently accepted medical practice might also jeopardise outcomes.

# 2340 3.7 Concluding remarks

As the above examples show, religion has multitudinous effects on the provision of healthcare at all levels.

Religious beliefs held by patients and practitioners have the potential to be negative. Physical and mental harms may take the form of self-imposed suffering, the imposition of the will on others who cannot defend themselves, exclusion, bullying and the consumption of resources needed elsewhere for more clinical demands. Conversely, however, religious beliefs held by patients and practitioners have the potential to be good influences. These benefits could be the providing of critical moral support in times of acute stress, making sense of the experience of illness, providing a sense of identity, encouraging caring behaviours and assisting in the recovery process.

A fully permissive, 'do not question' approach to religion in healthcare has the potential to open both patients and staff to the harms suggested above, allowing religious beliefs to dictate action in the face of limited resources, the coercion of people by others, through intractable suffering and sometimes to the point of death. However, to exclude religious beliefs from the equation entirely is to have a health service focussed only on the medical model of disease and ignore the benefits such a belief brings, as well as doing a disservice to the identity of believers. Religious beliefs are still important to individuals, and the NHS claims taking account of these needs is required.

## 3.8 Case studies

It is a characteristic of medical ethics that case scenarios are used as both illustrations of issues and as 'thought experiments' to relate ethical theory to real life medical practice. True life incidences are complex and often convoluted, so the cases are often simplified for the process of understanding key points. With Paganism, there simply is not the literature available to produce many examples directly based on actual Pagan cases.

The purpose of creating the cases below is to generate plausible scenarios in which Pagan beliefs generate issues of ethical concern in healthcare. They follow the case examples in the preceeding parts of this chapter because they are also examples of religion's intersection with healthcare. The cases also illustrate potential differences in health and care needs between the three key Pagan groups identified in 2.3.

The cases are occasionally linked in following chapters to discussions which relate to them, but their main use is in chapter eight (8.1 and 8.2). In that chapter, these hypothetical cases are used to demonstrate that my proposed methodology using Care Respect (Chapter Four) produces outcomes which are more ethical than those of two other weighting methods. These other weighting methods rely very strongly on the traditional view of religion, rather than more contemporary expressions of faith. Using these hypothetical (but grounded in experience) examples of Pagans within healthcare exposes the difficulty caused by focus on more traditional understandings of the Abrahamic religions.

The cases are based heavily on the Pagans with whom I am most familiar (in the 25-50 age bracket). According to the Office for National Statistics, census data confirms that the largest group of those with 'other' religion (which includes the Paganisms) are 25-49 years old (Office for National Statistics 2013). This age range means their (current) encounters

with healthcare are more likely to be on the basis of short-term, resolvable needs. A hospital environment (in which all doctors and nurses have at some point practiced) is a good basis for initial comparisons. Certain issues, such as medication refusal, concern about being judged/misunderstood leading to reluctance to discuss, and lack of staff understanding are common across other areas of health care, even though they are represented here in hospital scenarios. Nevertheless, there are also Pagans in need of long-term care for chronic illness, Pagans in residential care and Pagans receiving End of Life care (Smith-Stoner, Young 2007). Using the framework established in the thesis regarding more acute scenarios, drawing up further illustrative cases in community, reproductive and elderly care would be a valuable contribution to post-thesis work addressing the needs of this group.

#### 3.8.1 The Druid

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Paul is 45 and has polycystic kidney disease (PCKD).

He is admitted, as an emergency, to hospital suffering from chronic kidney failure- a complication of his kidney disease. Staff discover he should be having regular haemodialysis, but he has missed his normal appointment at his local hospital. An emergency dialysis is performed which delays the usual dialysis clinic slightly. With a reminder of the importance of dialysis, Paul is released back to his normal consultant once his condition is stable.

Back at his regular hospital, staff note he has a history of irregular attendance. Paul explains he is deeply unhappy at needing to frequently attend as this means he needs to live in a city away from nature. Since peritoneal dialysis ceased working for him, he is no longer able to do his job as an ecologist and it is important to him to visit remote places to attend rituals and be in contact with nature. He has tried to explain this before, but his consultant and a senior nurse both dismissed his beliefs and his hospital records still list him as no-religion.

He does not want to die, but he does not feel a life spent going into and out of hospital allows him to meet his religious obligations. He states he does not want to be dialysed again even if it will mean he dies.

In keeping with his animistic beliefs, which also lead to his being a vegetarian, he has refused to go onto the organ transplant register as this would involve taking in the essence of another being, even though it would mean a good chance of returning to his normal life. The staff are struggling to understand Paul's position, and have requested a psychiatric evaluation. A hospital chaplain is able to contact a Druid through the local interfaith forum. However, the Druid explains that the views of Druids are not unanimous on the matter of organ transplants and there is no central doctrine that requires abstention, although generally they do not object. The psychiatrist confirms Paul has capacity.

In discussion with the Druid visitor to try and find a suitable solution, Paul's 24 year old son Delwyn, suggests he might be a suitable kidney donor. He states that their close relationship represents an already shared spiritual essence. Genetic tests suggest that Delwyn has not inherited PCKD and furthermore is a suitable match.

Paul agrees that this would be acceptable but requests that the surgery is performed with a fellow Druid present in theatre during the operation to make an appropriate blessing. There is some concern his history of 'non-compliance' might make him a poor candidate for transplant. Members of the surgical staff object to this unnecessary alteration to procedure claiming it will distract the team, introduce an infection risk, and threaten the success of the operation. 'Plenty of people are scared of surgery but they don't let them have someone to hold their hand', they say. However, as the financial team are keen to point out, long term dialysis is more expensive than an organ transplant.

#### 3.8.1.1 Commentary

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Paul's case represents a refusal of a standard medical treatment, similar to the refusal of blood by Jehovah's Witnesses (Ridley 1999), raising familiar issues of consent and capacity, autonomy and beneficence. Unlike these more familiar cases, however, Paul's religious beliefs are unfamiliar to the staff, and his request for a spiritual presence in a surgical area is different from standard refusal examples (and from the usual examples of requests for 'medically non indicated care' that revolve around life prolonging technology). Although the similarities between Paul's refusal and that of Jehovah's Witnesses supports treating Pagan and JW refusals similarly, Paul's specific request enables me to examine the extent to which ethical factors other than resource allocation impact accommodation. For example, Paul's 'non-compliance' could be used to justify the withholding of an expensive resource which might be used elsewhere with greater success.

Although Paul and his case are a fabrication, Paul's beliefs around organ donation are derived from sources in the Pagan, and Pagan healthcare literature. For example:

To the \*Pagan, this is not an ethereal soul, implausibly attached, but deep in the subatomic matter, consciousness as stories, awake and vital in the patterns of energy, dancing in response to patterns around. As a result, many \*Pagans will not take part in the technology...(Restall Orr 2007 p.216).

Generally, Witches believe that if someone else has possession of one of their body parts (hair, nails, etc.), then that person has the potential to cause them harm. Therefore, it would not be unusual for an individual Witch to request a limb be returned to them after removal (Deerman, Rasmussen 1996).

There is a prevalent belief in the Craft that the soul not only transcends the body, but also immanently exists in the body's parts. Therefore, it is likely that a Wiccan faced with receiving a transplant would undergo specific rites to purify their body prior to surgery, to thank the donor, and to focus on integrating an organ from another into themselves (Slaney 2012).

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If I were to be involved in organ donation, I would like a chance to 'cleanse' the organ, or otherwise prepare it for entering a new body. I have read of people taking on aspects of the donor's personality or likes/dislikes etc and it makes perfect sense that the organ would carry energy that is suited to the donor (Anon quoted by Slaney 2012).

For a Pagan who holds that an 'essence' is a crucial part of an individual, bringing such foreign material into the body could be traumatic and dangerous. At the least it might threaten the individual's identity, and at worst override it. Paul would feel bodily violated and invaded by a transplant.

Living organ donations occur in the UK at around 1000 a year (NHS Blood and Transplant 2018 2017, Zelewska 2018 p.18) so the principle is well established. Medically the outcome is likely to be good from his close relation, and his son is able to consent freely to the donation, perhaps even encouraged to do so by his shared religious beliefs. However, access to donor organ waiting lists includes criteria around likely compliance with the post-transplant regimen (Robinson 2018 p.13). Although Paul is not seeking a short-supply donor kidney, for which the lists are arranged, this might make him a worse candidate for a successful transplant.

We might be inclined to think that Paul's request has the weight of a preference (and there is acquiescence to preferences all the time), but it runs deeper than that. Paul's identity will be compromised if the transplant continues without a spiritual supervision, and so he will refuse it and ultimately die as a consequence. If Paul's request is granted, he has a much greater chance of survival.

#### 2480 3.8.2 The Wiccan

Katy is a 21 year old female who had been involved in a fire. On admission she was barely conscious, and was treated according to her medical need, including the use of animal derived products. After emergency treatment she was admitted to the burns unit. On waking, Katy resisted pain relief for all but the most extreme pain and requested that she not receive animal derived treatments. On consultation with her Doctors, Katy was told she will need reconstructive surgery on her face and hands.

Katy accepts the need for functional repairs to her face and hands, but specifically asks that no effort be made to ensure a good cosmetic outcome. She wants the scars. At a meeting with the surgical team it is suggested it would be wrong to not treat her according to current best practice (in terms of both surgery and use of animal products) – which in her condition would yield a very good cosmetic outcome. The fact that the requested treatments are lower cost but less effective is raised. The consultant decides to ask why Katy has made the requests.

After some coaxing, Katy reveals she does not want cosmetic treatment as she believes the accident was punishment for her casting a spell with bad intent. She holds the belief that it is wrong to cause harm to others in accordance with the Wiccan Rede "an' it hurt none, do what ye will" (Adler 2006 p.79). She extends this to animals, including eating meat and the

116

use of animal materials in medical treatment. For some Wiccans, there is also a 'rule of 3-fold return', whereby the (negative) action done rebounds upon the actor magnified three times (Davy 2007 p.116). The injury is her reaping the just results of her intended harm. Conveying this information back to the surgical team, a vehement discussion ensues about whether she has capacity to make decisions about the cosmetic treatment given her beliefs. One of the surgical team asks if her consent would be informed if she did not know part of his surgical training in the USA involved practicing with animals (DeMasi, Katsuta et al. 2016).

#### 3.8.2.1 Commentary

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In this case, similarly to Paul's, I illustrate questions about capacity and acceptance of certain treatment types, such as those around medication contents (Enoch, Shaaban et al. 2005). Also illustrated are requests for non-standard/non indicated procedure (in Paul's case, for a spiritual element to the transplant, in Katy's declining the standard). Whereas many requests for 'extraordinary' measures in the general literature are around End of Life care (Orr, Genesen 1997), these are currently less relevant to the Pagan demographic of which I am a member. The lack of understanding by staff is presented as well (Smith-Stoner, Young 2007, Tejeda 2014, Anonymous Witch 2019).

Katy's belief in the threefold return seems to be an example of harmful 'magical thinking' (Matsumoto 2009) about cause and effect, perhaps suggesting she is not fully rational (see Chapter 5.2). No-one close to the healthcare team knows about Wicca and they have no basis on which to establish the standing of Wiccan religious beliefs or the role that it plays in the patient's life, although Katy does not seem to lack agency or capacity in other respects. Her reluctance to discuss her motivation could be interpreted as insincerity or as a lack of

117

faith in the underpinning belief. However, it is also likely that Katy is expecting to find her beliefs dismissed or mocked because of past experience of anti-Pagan attitudes.

#### 3.8.3 The Heathen and the Trekkie

Karen and Simon are both admitted, early morning, to ambulatory surgical unit for surgical repair following hand injuries the previous day. There is a good chance of full recovery of function if the surgeries are conducted within 24 hours of injury. The surgery is likely to be quite short, and the patient will probably be able to go home a few hours after the surgery is complete. There are no clinical differences between the two patients. Due to demands on the service, waiting times are variable. Both patients have requested if they can be seen early, as the longer they wait, the more likely it is surgery will require an overnight stay and not being discharged until mid to late morning the following day.

Karen is a devout Star Trek fan, who has tickets to travel to a conference the next day, and Simon is a heathen-inspired Pagan who has an important *blot* to attend in honour of midsummer that evening. Both have friends waiting for them who are travelling some distance to meet them.

Karen, who is wearing a Star Trek uniform top and is making jokes in Klingon with her friend, had saved for a long time to attend the convention tomorrow, with the opportunity to meet her favourite actors and meet friends from all over the country. The convention requires about 3 hours of travel. Most conventions are not held somewhere she can get to and this is the first year she has this opportunity. Simon, on the other hand, considers it a matter of honour to show hospitality at Midsummer, and exchange gifts and stories with kith and kin on that date. He has gone to considerable expense to arrange the venue and events for the evening. Neither are in a position to recover the expenditure already made.

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Both Karen and Simon are considered 'a bit odd' by the ward staff. Both Karen and Simon suggest to the staff that their reasons for wanting to be treated early matter. Both are upset that there is a possibility they would have to miss their events. Both are prepared to leave the hospital and try and get the surgery done later to avoid missing their respective events. Both are aware that the longer the delay the less likely it is the repair will be a success, and that it is possible their operations may take longer than expected, or potentially not work at all. Neither are received particularly well by staff on the busy day surgery ward who say they should just care about getting better, rather than a 'tv programme' or 'seeing their friends'. The team are inclined to settle the matter by randomly assigning them, seeing little difference between the two individuals, although there is some discussion as to whether the religious or non-religious belief ought to be given priority.

#### 3.8.3.1 Commentary

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This case is deeply reflective of my own experience, although with an added element of direct choice between patients. Both fandom and Pagan circles are familiar to my experience, and both can experience judgement from the mainstream (and within the group) for their views (Frazetti 2011, Gray, Sandvoss et al. 2007). In this hypothetical scenario, I illustrate two individuals with deeply held preferences about their treatment, one motivated by a religious obligation, and one by, in this instance, a purely personal interest.<sup>38</sup> This highlights the ethical question as to whether one or another is more deserving of being fitted in to a list. Both patients also find themselves treated by staff in a way that seems to

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<sup>&</sup>lt;sup>38</sup> In the previous chapter I noticed that there is a moral element to religion and a transcendent component. Fandom is, of itself, often compared to (civil) religion (Gray, Sandvoss et al. 2007), but such a discussion is beyond this thesis. It certainly seems possible that for some fans Trek gives a moral framework, however for the purposes of this case, the fan does not justify their request on the basis of the mythology or rules of Trek morality.

lack compassion and understanding, giving the opportunity to discuss what is required as a baseline ethical approach to people different from the staff under Care Respect. The hospital has the ability to accommodate the request of one, but not both of the patients, and which one is chosen is reflective of whether a religious belief might carry an additional weight in terms of being accommodated. Deliberately, both of these patients have something that is deeply important to them but that is likely to be considered fringe or weird by staff unfamiliar with either Paganism or the Star Trek fandom.

# 4. Care Respect for Persons

The preceding two chapters have illustrated that religious beliefs form part of the way of life for those who hold by them. Conflicts between the worldviews of religious believers and the worldviews of healthcare providers can lead to poor outcomes. The NHS principles recognise these points of conflict and seek to address them- patients should be treated with 'respect, dignity, compassion and care' (NHS 2015 p.3) and without unlawful discrimination on the basis of their religion (among other characteristics) (NHS 2015 p.6). Setting aside the role of law and rights for the moment (I return to these in chapter six) this chapter explores the relationship of treating patients with respect to the ethical foundations of respect for persons. In asking what respect is, and to whom/why we owe it - other concepts such as dignity, compassion and care become apparent.

I argue that we should respect people, and accordingly accommodate their religious belief, because of the way in which worldview beliefs -in particular religious beliefs- represent the reality of the individual and particular person who holds them. Not only are they the result of the abstract capacity for forming and acting in accordance with one's ends (of profound moral import for personhood), but they are embodied in the particular identity of the individual. It is not only the capacity for personhood that creates obligations for us; a shared interest in not being harmed and in avoiding suffering, and the vulnerability of others to our actions inform our respect (and our care) for others. I justify this with reference to the concept of care respect (Dillon 1992a).

In this chapter, I explore what it means to respect a being (e.g. Darwall 1977), and how the relationship between moral status (e.g. Warren 1997) and capacities of personhood (e.g. Beauchamp, T. L. 1999) shape our conception of respect for persons. Recognising limits to

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our conception of persons according to cognitive capacities, I illustrate the contribution of the feminist ethics of care (e.g. Gilligan 1993, Held 2006). Dillon's (1992a) concept of *care respect* brings these strands together, allowing me to apply care respect to Wreen's (1991) recognition of the type of belief that religious belief is as giving rise to our reason to accommodate belief.

Accommodating religious belief does not mean that anything goes, however. The constraints made by care respect impose legitimate boundaries discussed in chapter six.

# 4.1 What it is to respect

...respect is kin to esteem, admiration, veneration, reverence, and honor, while regarding something as utterly worthless or insignificant or disdaining or having contempt for it is incompatible with respecting it.

(Dillon 2014 [Online])

There are numerous different conceptions of respect, such that the concept is described as 'ambiguous' by Dillon (2014). In day to day life we speak of respecting our elders, respecting authority, respecting 'life choices', respecting life, respecting other people, respecting ourselves, respecting bodies, boundaries, achievements and opinions. We can have varying levels of respect, and we can respect in some categories and not others—respecting someone's skill as an actor but not their problematic attitude to women or to black people. However, labelling something respect-worthy signifies that we have good and reasonable cause to restrict or modify our behaviour and attitudes towards the thing we have respect for. We must then consider what kind of behaviour and attitudes would be appropriate given the nature of the thing concerned.

There are many ways of using the word respect that would lead us to modify our behaviour in many different ways. Hudson (1980), for example, characterises four forms of respect: obstacle respect modifying behaviour because of the challenge imposed by something, for example, a sailor's respect for the sea; directive respect, which is abiding by an agreement or instruction; institutional respect, which is behaving in accordance with the importance placed on social and institutional authority e.g. a judge or a doctor; and finally evaluative respect, an attitude of positive appraisal in accordance with its excellence by a set of criteria.

As my concern is with people, I will not consider respect in the sense of 'respecting bad weather because of its impact on driving conditions' or other prudential, non-moral forms of respect. My concern is with the kind of respect that requires an ethical approach – a form of moral respect.

When we are dealing with things that demand moral respect, respect is often intrinsically linked to the concept of moral status, that is things we can behave rightly or wrongly toward.

Mary Anne Warren summarises:

'to have moral status is to be morally considerable, or to have moral standing. It is to be an entity towards which moral agents have or can have, moral obligations. If an entity has moral status, then we may not treat it in just any way we please; we are morally obligated to give weight in deliberations to its needs, interests, or well-being... because its needs have moral importance in their own right' (Warren 1997 p.3).

Moral status is not synonymous with moral respect- according moral status is one way of showing moral respect. However, Warren's quote identifies something that is considered very key to the notion of moral respect, the need to give weight to needs and interests and well-being because those things are morally important in themselves. This in itself reflects 123

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what is perhaps the most enduring concept of what it is to respect persons - the Kantian maxim 'act in such a way that you always treat humanity whether in your own person or in the person of any other never simply as a means but always at the same time as an ends' (Kant 1991b Trans. H.J.Paton p.66). Following from this, Buss (1999) for example, considers respect to be recognising something as a 'source of values'. That is, something that is an end in itself is that which has the special ability to inform *our own ends* (Buss 1999 p.519 & footnote 4). Thus, this ability to make demands on us requires us to 'take other's points of view seriously' (Buss 1999 p.536).

I interpret 'seriously' here (and wherever I use it) as approaching something with the recognition that it *could* morally necessitate a change in our focus, attitudes and actions.

## 4.1.1 Varieties of Respect

Something fundamental about the qualities of the object of our respect places restrictions and obligations on how we are at liberty to treat it (either morally or prudentially). A basic respect offered to all entities in the category 'human being' would be what Darwall (1977) characterises as recognition respect (RR). There is no general agreement about what our exact obligations are *vis* that respect, but in the case of persons, we regard moral obligations arising just because they have the quality of being persons (Darwall 1977 p.40). Some authors relate this to the concept of inherent worth and / or dignity (Matiti, Trorey 2008 p.2710). In this section, I indicate that it arises from our seeing the appropriate properties of persons and *taking them seriously*. We can have RR for things other than persons, and if we are too selective about what we see when we respect people, we have failed in recognising the relevant features that ought to shape that respect.

124

Darwall (1977) identifies RR as the kind of thing that:

consists, most generally, in a disposition to weigh appropriately in one's deliberations some feature of the thing in question and to act accordingly... (p.38).

This could apply to a number of the ways in which Hudson (1980) presents respect, but importantly:

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[t]o say that persons as such are entitled to respect is to say that they are entitled to have other persons take seriously and weigh appropriately the fact that they are persons in deliberating about what to do (Darwall 1977 p.40).

Persons can be the object of RR, and such respect for persons has a moral quality. For some scholars, such as Downie and Telfer (1969), this kind of respect for persons is *the* central feature of ethics. For persons to be so valued, something about them must be intrinsically valuable: 'something that should be cherished because of what it is' and the essential features that 'make it what it is' (1969 pp.14-15). However, what prompts respect, and how we respond to it, is heavily contingent on the factors we chose as relevant, something explored in section 4.2.

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Darwall (1977) also identifies a second kind of respect, an *appraisal* respect (AR). AR exists when "its exclusive objects are persons or features which are held to manifest their excellence as persons or as engaged in some specific pursuit," (p.38). We might therefore have respect for someone's surgical skill, athletic prowess, musical talents, kindness, integrity or overall 'good' qualities. AR is therefore offered to something that has somehow

'earned' respect and theoretically can also, therefore, be lost (p.39). Conversely, RR can never be lost on the basis of behaviour or character.

Although *recognition respect* for persons is to always give proper weight to their being persons, *AR for persons* does not oblige me to morally behave in a particular way towards the object of my positive appraisal. I am not obliged, therefore, to attend all the games played by a particular skilled tennis player -I might not even like tennis but still respect their skill- in the same way as I would, however, be obligated to not run over said tennis player with my car even though I did not like either them or tennis.

AR has advantages. For example, we may want to negatively appraise the behaviour of a particular person (e.g. their racist jokes) as failing to show proper respect to persons. Darwall suggests that an important part of AR for persons is a concern with character and moral agency in a Kantian sense (Darwall 1977 p.44), a matter of how skilled at embodying respect-worthy traits you are. We censure people who behave in 'disrespectful' ways, through social and legal means (even though we may not fall below certain standards demanded by RR of their person-ness). In healthcare, though, there would be problems if our obligations to patients rested on our appraisal of them. For example, we might have more AR for the person who quit smoking (they fully enacted their desire to stop smoking), a dutiful, rule following patient who never missed their tablets (excelling at being a patient) or the person with a disability who 'never lets it get them down' (they are persevering, showing courage) or have less AR for people not deemed to be particularly accomplished at self-care (they lack self-respect), people who committed harmful acts, or people who exhibited poor impulse control. Sometimes, though, those who prompt the least AR are those in greatest need of help. Alternatively, the low level of AR could arise from a health

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professional's particular biases.<sup>39</sup> Generally,<sup>40</sup> requiring patients to be accomplished at a particular thing before helping is asking too much, which I return to in the next chapter. This makes AR a poor source of our most basic obligations, when compared to RR. Respect for patients seems much better served by recognition respect.

However, people in themselves do seem to want to have some measure of AR. People generally want *their* individual choices and activities to merit respect; wanting the ends they have chosen to be considered valid and worthwhile by peers. Theodore Benditt suggests (2008 p.490) that receiving AR is closely linked to our self-estimation and wellbeing, as we generally want others to go beyond the basic respect owed to all persons and be respected in ourselves, for *our* achievements and efforts. If people need consideration of their personally specific interests, abilities and roles, then failing to recognise them (that is, if we do not take them seriously) is not respect. However, AR for persons seems much more like an evaluative judgment that need not ever be shared with the subject of the AR, rather than something fundamental to all people. Perhaps, RR should incorporate the importance of what people see as 'their own' value, as well as one owed to all persons – a suggestion to which I return in section 4.4.

Importantly, Downie and Telfer (1969) ask what it is about the object of our respect that makes us value it as an end in itself. To be so valued it must therefore be intrinsically, rather

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<sup>&</sup>lt;sup>39</sup> For an example of appraisals shaping moral considerations, see discussions on the 'undeserving poor' in which poverty arises from moral failure and the sick are scroungers (Shildrick, Macdonald 2013, Garthwaite 2011). Appraisal respect seems to feed ably, and uncomfortably, into imposing moral judgement on personal circumstances.

<sup>&</sup>lt;sup>40</sup> Generally, because on occasion it a) might be more effective to secure some compliance before offering expensive treatments (e.g. bariatric surgery) and b) because we do not want patients harming others.

than instrumentally valuable. It is not enough to say persons ought to be respected, but that humans should be respected for what is valuable in them (1969 p.20).

Dillon comments that 'personhood is an essentially contestable, ideologically malleable concept, and so, therefore, is the concept of recognition respect... the concept of recognition respect treats personhood as a variable' (Dillon 1992b p.56). That is, the concept itself cannot settle the question of what a person is, we must know what the morally significant features of persons are in order to know how to respect them. Thus, different conceptions of the person entail different manifestations of RR; it would be more accurate to say that RR does not require attaching to a concept of 'person', so much as to the qualities they embody.

Most adult humans will possess the relevant features, as they are the paradigm example of persons. However, the situation is not resolved – we do not yet know *how* we should respect these qualities, or indeed, that we are recognising the right qualities. I shall concentrate, for this chapter, on the latter.

# 2740 4.2 Recognising patients as persons

As the NHS principles (NHS 2015) indicate, respect for the patient is at the heart of healthcare. Most patients in the NHS context are persons, and the highest forms of moral respect are generally reserved for the entities we call persons. If respect is due to the features of persons, then defining *person* in a moral or philosophical sense impacts on the moral obligations that we have toward them (or expect to be reciprocated). Our definition of person can determine how we might morally distinguish between foetuses, children and adults and thus be justified in treating them differently.

For example, Teichman captures the sense in which human being and person are synonymous:

The most common sense of the word 'person' is 'human being', and this is the sense which has moral import. For morality, if it exists for the sake of anything, exists for the sake of human beings, not for the sake of a philosophically defined set of rational substance (Teichman 1985 p.184).

Whereas, for Harris, being a person is not restricted to humans, but to creatures with a certain cognitive sense of self-value:

...if we ask "which lives are valuable in the ultimate sense, which lives are the lives of persons?," the answer will be "the lives of any and every creature, whether organic or not, who is capable of valuing his/her or its own existence" (Harris 1999 p.303).

Whereas Catriona Mackenzie for example, offers a far wider concept, related to the experience of living in a body and engaging with others;

To be a person is to be a temporally extended embodied subject whose identity is constituted in and through one's lived bodily engagement with the world and others (Mackenzie 2010 p.119).

A definition of person that focuses on person as synonymous with 'human being' or 'human animal' potentially underpins a moral condemnation of abortion and less concern about suffering in nonhuman animals, whereas a definition of person as 'an entity with a specific level of cognitive capacity' could exclude many humans but not all, while also including some nonhumans. Recognition of an entity as a person, therefore, seems to determine which, if any, inviolable moral obligations exist in our treatment of them.

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Because of the moral impetus provided by recognition as a person, recognition carries with it the benefits and obligations that go with that; involvement in a community of similar morality-capable persons, treatment of others and by others with moral respect, judgement, punishment, protection and support. Alongside this, it is an unfortunate part of the human psyche that we, at times, tend to withdraw membership of the moral community from those we dislike, searching for 'objective' reasons to exclude them – such as calling them animalistic. Examples include the dehumanisation of Jews in Nazi Germany, and of African slave 'cargo' in the 18<sup>th</sup> and 19<sup>th</sup> Centuries, enabling the exertion of power over these groups of people and contributing to their gross maltreatment (Goff, Eberhardt et al. 2008). This tendency to privilege 'people like us' as worthy of moral and social inclusion has consequences for how best to define person. As Jenny Teichman (1985 p.185) comments, the definitions of a person '... can have a dramatic effect on the outcomes of metaphysical, moral and political reasonings.'

# 4.2.1 The features of persons

In general language, person is used as synonymous with *human being*, but there is no implicit reason that person might also be used appropriately for non-human entities. Many arguments on the concept of a person exist, most of which identify shared cognitive features of adult human beings as the relevant factors. These are often called accounts of 'Personhood' and arise frequently in discussions of the obligations we should have to such entities as embryos, foetuses, and non-human animals. Key elements of personhood include (but are not limited to) rationality, moral activity, and the ability to create one's own

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purposes.<sup>41</sup> However, what counts as necessary or sufficient varies from one account to another.

Broadly, definitions of person fall into three types, those that are related to species (humans are persons) such as Teichman's; those that are hinged on some form of cognitive quality found in most humans (but not necessarily only in humans) such as Kant, Locke and Harris, and those based on some other wider criteria, such as Mackenzie's. The cognitive qualities associated with personhood are profoundly associated with 'respect for autonomy' to which I return in the next chapter. Here my focus is on the role of cognition in personhood.

According to Kant, it is the *rational nature* of persons, as 'ends in themselves', which constitutes the supreme limiting condition of the freedom of action of every human being (Kant 1785, 4: 431) establishing that we are not able to violate another's end. For Kant, every rational being, exists as an end in himself and not merely as a means to be arbitrarily used, unlike the non-rational:

Beings whose existence depends, not on our will, but on nature... if they are non-rational beings, [have] only a relative value as means and are consequently called things. Rational beings, on the other hand, are called persons because their nature already marks them out as ends in themselves—that is, as something which ought not to be used merely as a means—and consequently imposes to that extent a limit on all arbitrary treatment of them (and is an object of reverence). (Kant 1785 p.228)

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<sup>&</sup>lt;sup>41</sup> Tooley for example, lists 17 such characteristics (Tooley 2010 p.113).

For Locke, a person could be defined as '... a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places' (Locke 1690/2015) indicating that intelligence and thinking are the requirements, as well as an ongoing identity. Harris (cited above) builds on Locke in his discussion of moral status, returning to the idea of the persistence of self.

It is not clear that one has to identify as the same person over time in order to meet the criteria of being a person, as Locke stipulates. For example, if one lost all memories of their past, they would still remain thinking and self-aware, and we would not be inclined to think they were no longer a person *per se*, even if no longer the person they were. If, however, they were able to host all of their personality quirks and experiences in a machine, leaving behind an empty body, we might be equally disinclined to think the person was in the body. <sup>42</sup> Persons therefore do seem to be linked to some level of contemporaneous cognitive activity. Beauchamp (1999) summarises that the standard approach to defining a person is a

descriptive, philosophical matter of logically identifying 'the thing known as a person' as

<sup>&</sup>lt;sup>42</sup> A mind is not clearly something distinct from the body. There cannot be minds (science fiction notwithstanding) without some form of sensing, provided in all of the cases we know of by a physical body supporting a brain. A full discussion of mind-body dualism, and the extent to which bodies are constructed or materially real is beyond the scope of this work, but the rational-moral part of persons (at least of the kind with which we are familiar) is inextricably linked to a physical body, something Mackenzie's person definition captures. This body is, after all, the source of physical suffering, the responder to desire, the means for achieving goals, and a focus of self.

The literature on how we might identify ourselves as the same person over time often features science-fiction staples, such as brain transplants, duplication and consciousness uploads (Parfit 1971)(although these things may at a future point be possibilities rather than thought experiments). Although such discussions can have consequences for the way in which we interpret future wishes about what we want to happen to the person we think of as us if incapacitated by dementia or injury, this is not a unique feature of advance directives in the case of people with religious beliefs. As the focus of the thesis on respect for persons who are evidently currently particular persons, I will not examine these particular arguments further.

distinct from any other entity. I call this the philosophical person criteria (*p-person*) and those criteria are:

- (1) self-consciousness (of oneself as existing over time);
- 2830 (2) capacity to act on reasons;
  - (3) capacity to communicate with others by command of a language;
  - (4) capacity to act freely; and
  - (5) rationality (Beauchamp 1999 p.311).

Therefore, if patients (and more specifically for the thesis, patients with religious beliefs) meet these criteria, then they could be recognized as persons and accorded the respect that accords to these fundamental qualities.

## 4.2.2 Problems with the definition of persons

The strength of the personhood approaches is that p-person need not be synonymous with human being. On accounts of personhood such as Harris' – the self-aware cognitive requirements, such as thinking and self-valuing are not limited to a particular species, gender, sex or other trait. This is a strength of personhood criteria.

However, the level of self-awareness required by Harris does not develop in most human infants from the age of around 2 years and may be lost through injury or illness at a future point. If something like language is to be included, it becomes harder to consider non-humans such as the great apes. Kantian respect for persons is only available for entities with rational agency (Downie, Telfer 1969 p.21) capable of following the categorical imperative,

and therefore, it limits the respect we can have for something that is not capable of being one-such rational-moral agent.

Babies, those with advanced dementia or significant cognitive impairments are *also* patients in the healthcare sphere, so if we want to respect them, we need to consider alternative loci of respect. Perhaps most adult patients, including those with religious beliefs, could just be accorded respect on grounds of personhood. However, if there are other grounds on which respect can be accorded, it is a failure of RR not to see these and respond also to those qualities, as they too shape our obligations to persons. Personhood does not adequately capture the respect we want to show all patients.

#### 4.2.2.1 Criticisms of the conflation of moral status and persons

Warren identifies that 'personhood is more difficult to define than life or sentience, in part because there is a strong conceptual link between being a person and having full moral status' (Warren 1997 p.91). Tom Beauchamp (1999) argues that this is because the same word – person- is used to do two separate things; identify a descriptive category and confer a set of moral obligations. We find it hard to separate the two understandings because unsurprisingly, we rarely consider people as divorced from our moral thoughts and/or intuitions about them. This makes it difficult to understand what the core parts of a person are, and the respect we should pay them.

In the section above I identified the *p-person* criteria – those things that are commonly used to define a person. In and of itself, the identification of a p-person should have no moral content – being a p-person does not implicitly or explicitly contain any moral statement, any more than 'this a quartz rock, not a gold rock' has a moral content, it is merely a categorisation. Beauchamp identifies a second way in which we use the concept person - the moral sense, in which having the title of 'person' means someone is a locus of moral status

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(Beauchamp 1999 p.315) in the moral community, with the attendant benefits and obligations. I call this being an *m-person*. An m-person has the ability to engage in *moral* activity – that is, the ability to make judgements about whether something is morally right or wrong, to act in accordance therewith, and thus to do actions which can be judged in a moral sense. Moral agents are the 'paradigm case of moral personhood' (Beauchamp 1999 p.315). To be a paradigm case of personhood does require some cognitive abilities such as a level of rationality and self-awareness; but subscription to a *particular* moral viewpoint is not a requirement for moral personhood or moral agency. People with religious beliefs will likely fall into the category of m-persons, but that is not the only reason we pay moral attention to them.

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As Beauchamp (1999 p.310) points out, preconceiving the metaphysical concept of a person with moral obligations and respect-worthiness, is begging the question of what it is to *respect* persons and tempts us to include things we respect in the definition of p-person. If we value rationality, say, we are likely to use it to define persons and *idealise* people's abilities to be rational and/or to be moral agents<sup>43</sup>. If we idealise rationality as the source of moral obligation perhaps we are including more entities in the moral family than ought to be there, or excluding those who should be in it, if the criteria that form the basis of metaphysical personhood perform the dual role of both defining persons and their moral status. Perhaps we are omitting a very valuable source of obligation by focusing on reason and 'moral status'.

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Other entities are nevertheless seen as entitled to respect, the but the respect owed to nonparadigm entities derives from something else. Warren suggests that the solution is to

<sup>&</sup>lt;sup>43</sup> Again, linked to the concept of autonomy.

recognise that moral agency is sufficient for the moral status of personhood, it is not *necessary* (Warren 1997 p.120) for *only* moral agency to motivate the giving of status or respect. As Beauchamp indicates, we also have moral obligations that arise from reasons other than their being rational-moral minds - such as the capacity to feel pain, or experience an emotion.

#### 4.2.2.2 Alternative loci of respect

It is possible, in Kant, to find a justification for a form of respect that also necessitates making others ends one's own (Downie, Telfer 1969 p.24) in a limited way, via 'active sympathy'. However, although Downie and Telfer (1969) recognize the place of sentience and emotion in forming a respectful attitude- described as *agape* (p. 29)-, self-determination and rule following remain the central focus as the grounding of our reason for respect. Through *agape*, we may, through 'resemblance' to fellow humans, extend respect and concern towards those who lack those cognitive abilities. This does not require them to have moral agency, but still fails to afford them their own standing.

The primary means of identifying another source of moral respect is to consider the capacities usually absent from philosophical or moral personhood criteria. For example, the ability to experience pain, suffering or emotion because '[n]onpersons have many interests in avoidance of pain, suffering, and emotional deprivation' (Beauchamp, T. L. 1999 p.317). Considerable moral standing applies to things that can experience these states – in other words, things which are *sentient* – a particularly useful recognition because m-persons generally also share these characteristics.<sup>44</sup> Singer, in his work on moral respect for animals,

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<sup>&</sup>lt;sup>44</sup> And some p-persons may not (e.g. those with psychopathy, and potentially artificially intelligent entities of the future...)

stresses the importance of considering interests in not suffering equally across species - 'capacity for suffering and enjoyment is a prerequisite for having interests at all' (Singer 1975 p. 9)<sup>45</sup>, basing his work on Utilitarian concerns. Korsgaard (2007 pp.4-9) argues similarly, from a deontological perspective, that natural desires – such as avoiding pain and having affections should be given the same status other values that we respect. Mackenzie's person, a 'temporally extended embodied subject whose identity is constituted in and through one's lived bodily engagement' (Mackenzie 2010 p.119) particularly refers to what can be physically experienced.

It is not to say that persons may not have some qualities that modify how we treat them differently to non-persons. Warren criticises Regan's subject-of-a-life arguments because we would not have clear grounds for prioritising ourselves as humans over creatures with whom we cannot reason, such as the rats infesting a child's home (Warren 1997 p.117). Nevertheless, it seems logical that our desire to be treated ethically arises *because* we experience pain, suffering and emotional deprivation when we are not, and perhaps we want others to be treated ethically for the same reason.

Another source of moral standing might be derived from values placed on these entities by those who do have moral personhood, meaning non-m-persons (or entities) have value because m-persons give them value (Robertson 1995). This captures something of the sense in which Downie and Telfer extend *agape* (Downie, Telfer 1969 p.29). However, there is a risk attached to valuing something only where someone else finds it valuable, instrumentally or otherwise, regardless of whether it is actually deserving of consideration.

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<sup>&</sup>lt;sup>45</sup> Singer was accused of suggesting that cases of marginal status- such as human infants – could be used in experiments and the like. Singer's response was 'the aim of my argument is to elevate the status of animals rather than lower the status of any humans' (Singer 1979 p.68).

The value given by others can only be second hand, and it is possible it will be withdrawn at any time. If intrinsic value is critical to respect, RR for persons must encompass only that which is intrinsic to *that* entity, not what is conferred on it by others.<sup>46</sup>

The features of entities that require respect, on my account, include more than those which are granted simply by rationality and moral agency. They include the interests that accompany being embodied, vulnerable and connected – the feeling, experiencing and avoiding suffering that are not generally covered by personhood accounts. Connectedness and vulnerability are, however, a feature of some feminist approaches to ethics, which I explore in the next section.

## 4.3 Caring about patients as people (feminist ethics)

[A]ssumptions about gender have shaped not only the ways in which we think about men and women, but also the contours of certain fundamental concepts— from "motherhood" to "rationality"— that constitute the working tools of theoretical analyses

(Little 1996 p.2)

Many considerations of the problems with defining m-persons focuses on the possession of impersonal and abstract qualities by 'a person', whether the concept arises in the metaphysical or moral sense. This is not surprising, given the extent to which, Hume excepted, emotions and interpersonal relationships have been down-valued in the history

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<sup>&</sup>lt;sup>46</sup> Even under a Utilitarian conception of suffering, we would struggle to extend respect to something which cannot experience suffering like rocks, trees and 'habitats', although the extrinsic value given by moral agents to these might give some weight to respect-worthiness, and the loss of habitats may cause suffering to nonhuman animals. Respect for the something like 'the environment' is often discussed solely in relation to its instrumental value, rather than its intrinsic value.

of 'Western' ethics. Yet, as Farley (1993) comments, '[w]e are who we are within social, cultural linguistic contexts... we do not produce our own meaning out of nothing (p.195).

Much work in feminist ethics explores a deficiency described by Stoljar (in an entry for the Stanford Encyclopedia of Philosophy) as:

arising from "masculinist" ideals of personhood that presupposed a conception of the person as "atomistic", ideally self-sufficient, operating in a vacuum unaffected by social relationships, or as an abstract reasoner stripped of distorting influences such as emotions (Stoljar 2018)

If accounts of the person rely on a conception that discounts half the global population, then respecting patients on that basis requires at least a re-examination. I will also return to feminist ethics in the section on autonomy in chapter five.

Through the twin strands of androcentrism and rationality, Little (1996 p.2) observes that distinctions between male and female have led to the down-valuing of women in philosophical (and broader) thought. This down-valuing has had broad influences across ethics and bioethics. *Androcentrism* is the way in which man is treated as the 'standard human', and woman as variation (deviance, underdevelopment) from the 'normal' pattern. Androcentrism has undoubtedly influenced the second difficulty, the predominance of gendered concepts of rationality in the discourse (Little 1996 p.9), which has associated the rational and mind (human) with the male, and the emotional and body (animal) with the female. Little notes that philosophers whose work still has influence have contributed to this situation. These esteemed philosophers include Aristotle, who described women as a mutilated males who have rationality without authority; Rousseau, who suggested that the search for abstract and speculative truths, principles and axioms '…is not within the competence of women'; and Kant, who asserted that "women's philosophy is not to reason

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but to sense"(Little 1996 pp. 9-12). As a result of this, and the confusion between moral and metaphysical personhood, traits associated with women have been excluded from consideration as morally valuable. Women themselves are not seen as p-persons and m-persons as fully as men are. This appears to be a gross oversight that limits the involvement of half of the human population from moral affairs; an indication that perhaps we are too restrictive in what we take seriously.

In *Women and Moral Madness*, Kathryn Morgan articulates the impossibility of being seen as a moral agent as a woman under these conventional influences (Morgan, K. P. 1987). Little (1996) notes 'it is man, and what is accomplished in the public sphere, that represents the human ideal (a view reflected in history books, which are histories of wars and political upheavals, not of hearth and home)(p.11). The influence of gendering is felt across a spectrum of areas from the exclusion of women from medical research, the low pay given to caring work, and the mistreatment of gay or 'feminine' men. 'Having balls' (in the sense of testicles, not dances) is good as it represents (male) courage, 'throwing like a girl' is badbecause not only is 'femaleness' seen as inferior, but also as childlike.

The standard theories of ethics (as they relate to persons), consciously or not, have therefore been influenced by gender and gender assumptions. One particular area in which this has been addressed is through the notion of an alternative 'ethics of care', suggested by Gilligan in 1977.

#### 4.3.1 Gilligan and the ethics of care

Gilligan (1977, 1993) conducted research around moral decision-making in women, finding not that it was inferior, but that it was what she identified as 'a different voice'. She subsequently argued that there is a different kind of morality, sometimes referred to as the

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ethics of care, that distinguishes between an impersonal, justice-oriented, what-we-owe-moral-equals kind of respect typical of men, and a compassionate, responsibility and relationship-centred ethic typical of women. The different voice is one that discusses moral problems as arising from conflicting responsibilities rather than from competing rights and:

requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract. This conception of morality is concerned with the activity of care and centres moral development around the understanding of responsibility and relationships, just as the conception of morality as fairness ties moral development to the understanding of rights and rules (Gilligan 1993 p.19).

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Gilligan criticized the moral development theories of Kohlberg (1981) -with whom she had previously worked (Kohlberg, Gilligan 1971)- because Kohlberg saw moral development as understanding impartial rights and justice. At similar ages to the boys and men he interviewed, women were talking about context-dependent rights and wrongs, thus, women were not as morally developed as their male peers, nor would they be unless they entered the 'public' sphere (Gilligan 1993 p.18). For Gilligan, this idealization of justice-based normativity overlooked the importance of feeling, contextual nuance of the circumstances and appropriate response, and abstracted moral actors from 'the network of identity constituting and affectively mediated interpersonal relations that makes up the fabric of their moral lives in order to render a "just" decision' (Wright 2004 p.52).<sup>47</sup> Women's voices

<sup>&</sup>lt;sup>47</sup> Although Wright criticises the accuracy of the objections to Habermas (whose work on morality informed Kohlberg) in particular, the summation of the gist of the complaint is representative. Whereas some some feminist authors, such as Benhabib (Benhabib 1992) have profoundly disagreed with Habermas, other such as Lugones (1987), have found Habermas' work not so exclusionary of context. A full analysis of this particular debate is outside the remit of the thesis.

are important, says Gilligan in her preface to the 1993 edition of her book – 'to have something to say is to be a person' (Gilligan 1993 p.xvii) but a voice must also be heard and attended to by another: '[S]peaking demands listening and being heard; this is an intensely relational act'.

The idea of an ethics of care was subsequently developed by feminist authors, such as Ruddick (1980), Noddings (1986), and Held (2006). Held (2014) comments that such things as social contracts, Rawlsian judgements, impartial Utility or Kantian moral duty 'miss the importance of the emotions for understanding what we ought to do, and for motivating our morally recommended actions' (p.109). Unlike the dispassionate and impartial nature of utilitarianism or deontology, care ethics draws on an experience of caring or of being cared for/about which is at least as universal as human rationality (Osuji 2017), if not more so. Something like empathy (for example), which is missing from the principles of conventional moral theories, might be essential to meeting our moral obligations; in care ethics people are instead morally motivated by the demands of other's vulnerabilities (Nortvedt, Hem et al. 2011 p.193) not their rational nature as persons. Care is also responsive to the obligations of relationships in which the agent and the person for whom they care are situated. Under care ethics, having greater obligations to those with whom we have bonds, such as friends or family - a difficulty for impartial theories- is not seen as an unwarranted prejudice; for example, having an obligation to rescue one's own children first. Carse and Nelson (1996) add to this by stressing that care ethics is not limited only to the personal or proximal. We can see vulnerability in others regardless of our personal relationship with them.

Therefore the key characteristics of an ethics of care are its' *particularity*, whereby the context of the moral decision hinges on the particular circumstances surrounding it, rather than (solely) on theory or broad stroke 'justice'; and the focus on a moral responsibility for

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the wellbeing of others with whom we are in networks of relationships. Human persons, to whom we apply morality, are innately particular, because each is individually placed and formed by goals, ideas, experiences and relationships, the nature of which differ from person to person. Given the differences that exist among individual patients, listening to their individual voices is part of a care ethics formulation.

#### 4.3.2 Criticisms of care ethics

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Three particular critiques of care ethics are that it lacks distinctiveness (compared to other theories), cannot give clear action guidance, and that it further contributes to the oppression of women by associating caring with women.

Concerning the first of these, Care is often linked to virtue ethics, because of its demands for a personal disposition towards caring. Halwani 2003 suggests subsuming care ethics into a virtue of care; Curzer (2007) finds ten counts of similarity with Aristotelian 'friendship' and thus argues care is insufficiently distinct from virtue ethics to constitute a self-sufficient theory, and Tong (1998) also considers care a form of virtue ethics, albeit a distinctly feminist one. Edwards (2011), finds it ontologically difficult to identify what care is, and sees care ethics as fundamentally compatible with Principlism (itself an approach that crosses theory boundaries)— at least in the nursing context. If it is compatible, Edwards argues, then perhaps it is not a stand-alone theory. However, Principlism is intended to be broadly compatible with both Deontology and Consequentialism as well; it is meant to articulate healthcare specific rules derived from common morality rather than be a stand-alone theory itself. This does not, therefore, seem fully appropriate grounds to discount care as a theory. On the difficulty of finding clear action guidance, Allmark (1995) does not find care a suitable basis for ethics, because care is morally neutral not essentially good, and thus could

not be an independent theory. His paper is based on very early conceptions of the ethics of care and an over reliance on the semantics of the word 'care', although Allmark identifies that it is not clear exactly how care can offer clear guidance on what to do in a given situation. Because it is contextual, and relational, it does not offer an overarching concept of what is right. The requirement for a theory to offer such a concept of 'absolutely right' is illustrative of the problems feminist ethics has identified; the need to find the single 'right' answer is in itself problematic.

On the final issue, that of reinforcing stereotypical femininity, part of the work that Gilligan (1993) did, revealed that women often felt that their opinions were unimportant, that they were profoundly concerned with what others thought of them, and that sacrificing oneself was deeply moral (p.67). Tong highlights that self-sacrifice has long been an overemphasized requirement for women, that idealising the maintenance of relationships is potentially damaging to women's interests. Whereas Noddings (1986) sees the highest form of ethics to be an absolute obligation to care for someone with whom we have some manner of relationship (Tong 1998 p.149) Tong argues this traps women in structurally oppressive and violent situations; Houston (1987) also urges caution on relying on 'womanly virtues' that are the product of oppressive patriarchy. Whereas it would be a bad thing for women to stop caring and nurturing (because caring and nurturing are good), work is required to value that caring properly and free it 'from patriarchal structures that would misuse or abuse it' (Tong 1998 p.150). Kuhse (1995) is also concerned that abandoning wide view, impartial issues of injustice would make it difficult to fight structural oppressions, but Carse and Nelson suggest 'we need not think of such relational models as exhaustive in order to take them seriously as sources of moral insight and key objects of ethical attention' (1996 p.26) meaning care is part of, not the entirety of ethics. Held, however, is vocal that viewing 'the

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ethics of care as supporting the traditional subordination of women is seriously mistaken' (Held 2014 p.107) because the practices and values of care are *mutual*, something absent in oppressive care situations. Dillon returns to the issue of respect here, and suggests that 'recognition self-respect is the appreciation of my intrinsic worth; it says I may and ought to take care of myself, not only or primarily so that I am better able to care for others, but in the first place because I matter in my own right' (Dillon 1992b p.62).

Although none of the criticisms has yet been fully resolved, care ethics remains a powerful challenge to the omissions of earlier theories. Demanding everybody *care* is a significant, and feminist, departure from conventional moral theory. Care ethics thus adds another dimension to considering the treatment of people with religious beliefs in healthcare. It demands that attention be paid to them in their precise situation as the person they are. Not only is this a function of caring for someone's wellbeing (not a strange inclusion for healthcare) it is also something that has consequences for our conception of respect. If the uniqueness of individuals is an essential to who they are, then respect demands this uniqueness be considered among the respect-worthy traits of who they are. These traits include not only their consciousness and sentience, but their beliefs, their worldviews, and their identities. In short, their chosen ends. There is also something particular about their position as patients that needs attending to, and that is their vulnerability to the authority of the healthcare institution, in which their voices may become lost. This can be seen reflected in the words of Rader (1964 cited in Dillon 1992b) and Farley (1993):

Respect for a person includes respect for this core of individuality . . . [and] appreciation of... the individual and human me (Rader 1964 p.157, cited in Dillon 1992b).

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In Farley's feminist version of respect for persons:

it is important to keep trying to articulate the unconditional value of persons – valuing as ends in themselves and avoid abstracting their histories and needs, address otherness without devaluing whoever is the other (Farley 1993 p.195).

In the following section, I explore bringing together care and respect. The relationship of care to the concepts of autonomy and benevolence is more closely explored in the next chapter.

# 4.4 Care respect (CR) – a special type of respect

As the general conceptions of respect and persons discussed above illustrate, respect for persons is often based on an impersonal or rational/moral interpretation of 'person'. This gives rise to a responsibility to respect these features in others, and we respect persons inasmuch as they represent a category of rational beings. However, not only should entities be owed respect for those reasons, but for their capacity to suffer and be harmed. A responsibility to not harm others in their particularity gives rise to a demand to care, something which is not generally held to be as universalizable as 'personhood'.

Care and respect often considered as opposing concepts, with Kant characterizing them as the principles of *mutual love* that admonishes men to come closer to one another, and of *respect*, which is to keep themselves at a distance (Kant (1797) 449). That the one is necessarily in tension with the other, however, is not inevitable. Some advocates of feminist and/or care ethics (such as Baier and Dillon, below) consider that both an impartial/justice-oriented morality and a particular/care-oriented one can be compatible moral foundations.

146

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For example, in *Science, Morality and Feminist Theory* (1987) Annette Baier asked for (a la Gilligan) a 'a marriage of the old male and newly articulated female...moral wisdom, to produce a new co-operative moral theory that harmonizes justice and care' (p. 59). Robin S. Dillon thus proposes the concept of care respect (CR) in response (1992a), which Carse and Nelson describe as a step towards;

a normative conception of care that does not ground it solely in love and affection for those whose connections to us are visible, but that urges respectful, compassionate concern for the welfare of others even in the absence of bonds of affection, or of relational, geographic, or cultural familiarity (1996 pp.30-31).

Dillon (1992a) describes CR as 'caring for a person as a way of respecting her' (p. 4). For Dillon, there is a form of respect that involves "cherishing some object, regarding it as having great value and as fragile or calling for special care... the kind of thing upon which we act or forbear to act out of benevolent concern...' (Dillon 1992a p.112). An example of such a respectful attitude is someone who protects the respect-worthy environment, or in someone who decries the vandalism of a respect-worthy rare artwork. This type of respect is logically owed also to persons.

A concern with cherishing and benevolence towards certain objects shares characteristics with care ethics *and* also with Downie and Telfer's more Kantian respect (1969 pp.14-15)- and therefore suggests a starting point for a fusion between care and respect. CR implies that we owe respect not just to rational/moral equals or those who are respect-worthy by

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achievement of excellence or instrumental or symbolic value,<sup>48</sup> but that we owe respect in the form of *caring about* the unique (and vulnerable) other.

Under CR, when considering a person as a person they are not only a 'representative of the category of persons' (whether p-persons or m-persons). Persons are also *specific* individuals with their own self-conceptions and points of view, situated in their own experience and networks of others (Dillon 1992a pp.115-116).<sup>49</sup> That a person exists in *their* environment and *their* physical form, and in *their* relationship to others, therefore must also shape how we meet our obligations towards them- using 'sensitivity and responsiveness to another person's emotional states, individuating differences, specific uniqueness, and whole particularity' (Friedman 1987 p.106). For Dillon, ignoring each person's uniqueness (much as the loss of a rare species or original artwork shows disrespect for its uniqueness) loses something essential about why we ought to respect them. 'What we ought morally to value and take account of (Dillon 1992a p.117) are precisely the details that make each person the unique person she is. We ought to respect, that is, the reality of our human individuality' (Dillon 1992a p.117).

Dillon identifies that elements of fundamental particularity and interdependence, loving attention, understanding and active sympathetic concern (for people and their ends) are features of the care perspective. Care, therefore, is a kind of RR for persons (or other entities) that engenders our treating them in a particular way (Dillon 1992a p.115). Care respect for persons is 'grounding our intrinsic moral worth in what we might call our individual and

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3160

<sup>&</sup>lt;sup>48</sup> This recognition of the value of care in discussions potentially also offers us a means of making respect for nature and respect for the environment normative.

<sup>&</sup>lt;sup>49</sup> This includes ourselves, with our own points of view, goals and experiences.

human 'me-ness" (p. 118) rather than as a mere representative of a category of *persons*, in the impartial sense. This recognition is about a true seeing of the unique individual.

Whereas Kantian respect is compatible with indifference, disinterest or even hatred towards others, care respect demands a commitment to attend to, i.e. take seriously, the nuances and subtleties of individuals (Dillon 1992a p.120). Dillon supports this claim with other authors who consider that it is necessary to see people beyond the label 'person' in order to respond ethically, including Bernard Williams' argument for 'identification' (1978), Lorraine Code's suggestion to know other people and their situation empathetically (1987a) and Spelman's conception of seeing people as who they are in their own view (1978) rather than through our own favoured lens. Under CR, even ordinary, imperfect, limited and inadequate parts of our persons – persons as we are now – merit respect and care (Dillon 1992a p.121).

A concern of the standard/justice account is that fundamental ethics must not treat persons differently -at least in the absence of intellectually accountable morally relevant differences (Downie, Telfer 1969 p.43). It must be *impartial*. Impartiality, Jaggar suggests (1989 p.97), is profoundly linked to both equality (equal worth of persons) and rationality (lack of bias), so in the absence of impartiality there is a question raised as to whether equality is supported by partisan obligations to those with whom we have relationships. Thus, care or other feminist ethics might seem to not consider all persons as equal, allowing for a moral favouritism.

However, Dillon argues that on the contrary, care respect clearly confers equal moral worth to all persons (and does so giving value to a wider and more inclusive understanding of what has value in persons). Taking that worth *seriously* means respect must include the requirement to see precisely how *this particular person* is situated. 'The aim of care respect is to keep in sight both the fact that this person is the unique individual she is and that she

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is but one among innumerable fully specific and unique individuals' (Dillon 1992a p.122). To respect a person requires seeing them fully.

I note that 'seeing others as they are' can be jeopardised by something which Frye (1983) calls arrogant perception. Arrogant perception is 'dis-integrating an integrated human organism and grafting its substance to oneself (Frye 1983 p.66). An arrogant perceiver (AP) (unwittingly, perhaps) sees and organizes the world and everything in it with reference to AP's particular desires and interests. Things that do not match the AP's expectations or demands are seen as damaged or faulty; 'he arrogates everything to himself and thus perceives as healthy or right everything that relates to him as his substance does when he is healthy' (Frye 1983) p70. Frye sees AP as something men have with regards to women, but AP is also done by women to other women (who do not fit the arrogated ideal proposed initially by men), and by white feminists to feminists of other ethnicities (Lugones 1987).<sup>50</sup> The opposite of the arrogant perceiver is the loving one, which is a 'matter of being able to tell one's own interests from those of others, and of knowing where one's self leaves off and another begins' (Frye 1983 p.75). If respect is ultimately derived from what we perceive (recognise), then our perception should not be limited by our own viewpoint and accompanying assumptions. A loving eye does not force the other to experience the world by way of the seer's interpretation (Frye 1983 p.82). CR, then, advocates seeing with the loving eye.

We *are* all different and must negotiate those differences, whilst nevertheless all being worthy of attention, consideration, care, concern and understanding. Particularity in

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<sup>&</sup>lt;sup>50</sup> I might add, by some secular physicians towards religious individuals and some religious individuals to the secular. The arrogant eye sees things like the seer as good, and the unlike or resistant as deviant.

respect would not be unfamiliar to parents of more than one child, or people with more than one friend (Dillon 1992a p.122), both scenarios being examples of respect and love given to people whilst appreciating, responding to the unique features of each, and promoting their different needs of wellbeing. As Friedman characterises, 'particularity does not exclude a common nature... We still deserve equal respect in virtue of our common humanity. But we are also more than abstractly and equivalently human' (Friedman 1987 p.109).

Some may also be concerned that care respect advocates a paternalistic 'taking care of others, something which may smother the individual beneath the well-meaning or controlling intentions of another. However, Dillon reiterates that we need to be promoting what *the other person thinks is important*, something only possible if we gain meaningful understanding of that person.

If there is to be care respect, and not just paternalistic taking care of, then we have to promote what the other person regards as important; or where that is not possible or where we cannot bring ourselves to do that, then we at least have to take account of her conception of her own good. And that, too, requires informed understanding (Dillon 1992a p.125).

Dillon suggests that even in this instance we might find ourselves thinking the other person is sorely mistaken, but we are still obliged to acknowledge the individual's sense of self, not necessarily taking it as true but still taking seriously the possibility of truth in it because it is so important to that person and to their understanding of who they are (p.126). We need not completely abandon *our* sense of what is moral; if our commitment is to the value of all persons then we cannot allow others to ignore such a value, but we cannot do so without attempting to understand why their values differ. I return to this in my discussion of tolerance in chapter six.

As an integral part of care respecting, we must avoid our tendency to project our own needs and understandings onto the other, making assumptions only cautiously as a last resort, and be wary of our own arrogance. CR ultimately calls for a lot of effort to open ourselves to that kind of understanding, something which, given human limitations, cannot be entire, even at its best. Dillon recognizes that the demands of CR are extensive. We are not ourselves exempt from frailties, imperfections and uncertainties, so developing the kind of attentiveness and concern CR advocates is an ongoing process. However, Dillon reminds us that 'what we owe others is our sincerest *efforts* to understand them... and an appropriate sense of humility about our access to others and about our own abilities to understand' (1992a p.127).

#### 4.5 Respecting (persons with) religious beliefs

A care respect model acknowledges that our obligations to others entail taking those others seriously, which would include respectfully considering<sup>51</sup> and responding to their religious beliefs. I do not argue that religion is of itself respect-worthy, but instead it is the identities of people to whom it is important that demand consideration. This is not to make the overly bold claim that religion cannot ever be important in and of itself, rather that *it is not necessary* for it to be so in order for us to accommodate the religious beliefs of Pagan (or other) patients.

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<sup>&</sup>lt;sup>51</sup> Taking something seriously is demanding, but it does not require an absolute change in one's own ends in response, so I use *consider* here, rather than arguing that such beliefs must always be accommodated. There are weighty ethical considerations, themselves derivable from care respect, which may limit our ability to accommodate the beliefs. These limitations are the focus of chapter six.

Respecting religion, in common parlance, can mean; respect for the rules of a religion (by following them), respect for the icons, buildings and other items of religion (by admiring the artisanry and craftsmanship therein, and /or by not touching, defacing or destroying them), respect for the religious identities of the people who follow the religion, not mocking or denigrating the beliefs and practices of religious people, or respectfully offering the moral codes of religion as deserving of a place at the discussion table. However, my concern is the people who hold religious beliefs. Religions themselves are not persons, either metaphysically or morally. Instead they are abstractions, albeit also concrete organisations in their own right, that cannot experience a personal desire or personal suffering, although it is possible to take them seriously.

In CR, we respect people because of a combination of their capacities (including the capacity to be harmed), their ability to have ends of their own, and because we can cherish them as particular individuals. Religious beliefs inform and influence the people who hold them (and take holding them seriously), thus religious beliefs must play some part in our respect. A significant part of this is to attempt, honestly and caringly, 'see the world through their eyes'. This entails exploring and understanding the role religion plays in that person's life, and promoting, at least as far as we can, their version of the good.

#### 4.5.1 Wreen and 'life reconciling' beliefs

Wreen (1991) argues that there is something about belief-based refusals of care to which we are more sympathetic than say, arbitrary refusals of care, given that we are legitimately concerned when patients opt for death. This 'something' adds weight to the patient's autonomous refusal, rather than it being a matter of simple wilfulness or eccentricity. This

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'something', according to Wreen, is religious belief. More precisely, it is the type of belief that a religious belief is, the role it plays for the believer, that grants weight to it.

Religious beliefs and values (illustrated in chapters two and three of the thesis) typically reference facts of human life that may be uncomfortable but necessary to bear: the inevitability of death, the need for sustenance, the circumstances of our lives that we do not choose, the limitations of what we can (or should) achieve or choose, the consequences of our actions, and the necessity of sharing an indifferent world with others (Wreen 1991 p.128). An arbitrary, random decision would lack this reference.

According to Wreen (1991), religious beliefs and values can:

circumscribe and interfuse other beliefs and values, and permeate all of them to some extent. That's why they're not of the same order, cognitively or valuationally, as other beliefs and values (p.128).

We would, therefore, respect a practicing Jehovah's Witness' active refusal of a transfusion more readily than a random refusal because of the:

supremely important integrating and reconciling function that [religious beliefs] have in a person's life. In an important sense, they fill out the person, and are integral to his personal identity and sense of himself (Wreen 1991 p.128).

When Wreen talks about the type of belief that religious beliefs are – how they are all encompassing and requiting, it is impossible not to compare them to the way of life and worldview referred to in section 2.1.6 *et seq.* Religious beliefs perform a 'life-reconciling' function that is critical to the meaning a person finds for themselves, and this life-

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reconciling nature is the reason religious beliefs<sup>52</sup> should carry justificatory weight<sup>53</sup>; to do otherwise is to fail to pay the proper attention to the individual concerned. Importantly, it is the *type* of belief and its impact on the particularity of the person that does the work, not the religion itself, so it applies to Christians, Hindus, Buddhists and Pagans equally. Moreover, because other beliefs besides religious ones are capable of fulfilling the role of a worldview, non-religious beliefs (such as vegetarianism, humanism and other secular conceptions) are also deserving of this kind of consideration. To respect a person in their particularity means to take seriously their beliefs.

#### 4.5.2 The moral impetus of religious belief

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There is a second reason for engaging positively with those who hold religious beliefs. Religion does not just give a sense of identity, but also obligations (section 2.1.3). When patients refuse treatment or request some specific accommodation on the grounds of their belief, they are responding to moral obligations— not mere 'preferences'. Moral agency, as Warren noted (1997a p.120), is clearly the kind of thing that accords a maximum of respect. These moral commitments need not be religious in origin, they can derive from other sources and could be found, for example, in feminism, environmental activism, or secular humanism. These commitments might be considered as, and in many cases are, expressed as a sense of duty; they may be tiresome at times, and may involve putting oneself in discomfort (a commitment to ensuring adequate blood for those in need means suffering

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<sup>&</sup>lt;sup>52</sup> Although in the article he uses a language typical of mainstream Western religions – having a Supreme Being and referring to said being as a He, Wreen expressly opens the door for other ideologies that perform the same role.

<sup>53</sup> At least in the refusal cases Wreen discussed.

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the needles of donation), at a disadvantage (calling out sexist behaviour in the work-place may have professional costs), or even in physical danger (the activist lying in front of a bulldozer, the soldier defending their county).

Importantly, we see that a duty or a promise is morally significant. All other things being equal we willingly facilitate them. For example, we would probably allow someone to take a short notice leave of absence if their partner went into labour early (because attending a birth with your partner is considered a serious obligation producing promise). We probably would not allow them to do so for attending a football match (or if the employee's presence at work had life-saving consequences as a countervailing duty).

This is strongly related to the concept of integrity.<sup>54</sup> When there is a conflict, integrity represents the point where we will not override a particular duty because to do so would compromise it (and ourselves) entirely. Calhoun (1995 p.257) asserts that integrity 'is being responsible to, and before, others for one's moral judgments', which requires that one take one's own judgments seriously and stand by them. Magelssen describes integrity as refusing to do the kind of thing you could not live with yourself for doing (Magelssen 2012 p.18). In his example, performing an abortion changes you from being someone who does not take lives into someone who does. Contravening religious duties changes one from a person who does not break promises to someone who does, from someone connected to the transcendent to someone cut off from it. Whereas integrity is sometimes criticized, as it might lack normative constraint or result in moral danger through uncritically being

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<sup>&</sup>lt;sup>54</sup> The nature of integrity is a supplement to, rather than an explanation of why respect is owed. In this light, I do not undertake a significant expansion of what integrity is.

partisan to one's own views (Scherkoske 2010 p.337), it functions as a general guide for our preparedness to look favourably on those with whom we morally disagree.<sup>55</sup>

### 4.6 Care respect and religious beliefs- concluding remarks

If we are to avoid the conflicts outlined in chapter three, then some means of accommodating the needs of those with disparate worldviews is required. If we had no respect for people *per se*, then we could simply apply evidence-based treatment to patients regardless of their wishes in the matter, but this would be to ignore something very specific about respect for persons. Prompted by NHS principles regarding respect, the purpose of this chapter was to explore the grounds on which we respect people. Religious beliefs are not people, but they are held by people – when someone asks for their beliefs to be respected they are asking for themselves to be respected- the respect is due to people not to any particular strand of religion.

Recognition respect is the type of respect we have for something based on intrinsic qualities it possesses; according to this conception of respect we owe persons respect because of the intrinsic qualities of persons. The alternative, appraisal respect, is to evaluate some manner of excellence – which permits us to engage, sometimes critically, with particular beliefs but does not ever replace our basic RR for persons. What the intrinsic qualities are *vis* according the highest level of moral consideration is the subject of much discussion. In general, persons are accorded this status on the basis of cognitive qualities and moral agency,

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<sup>&</sup>lt;sup>55</sup> In the classic example of a lack of normative constraint, some Nazis are considered to have had integrity, but the result of that integrity was morally reprehensible. What this suggests is that we recognise the sincerity involved in acting in accordance with one's beliefs – but this does not entail we must consider the belief itself acceptable. There are some things perhaps so incompatible with human vulnerabilities we would lose our own integrity to permit them.

respecting others as the bearers of rationality. Whereas some cognitive traits are useful for grounding considerations of personhood and moral status; the ability of something to suffer harms, and to have an interest in avoiding harms, (including physical suffering, violations of self and identity and the setting back of our interests and our ends) is a primary source of moral respect. It is one shared by those with cognitive capacities. There is a risk of idealizing rational/cognitive traits, and excluding other relevant considerations, something captured by the feminist ethics of care. Care instead requires recognition of the unique identity of the other (it is particular) and urges us to consider our responsibility towards them.

Although care and respect are sometimes seen as antagonistic, Dillon's care respect envisions a kind of respect that is attentive to both the qualities of persons (as rational entities or as feeling beings) and the individuality of people. It is therefore not possible to properly have RR, without recognising the individual's concrete particularity; religious beliefs are one such source of particularity. Thus, a respect that did not take seriously the religious beliefs that are features of the morality and identity of those who hold them would have failed to be a proper RR. Not considering persons with religious beliefs means we are causing harm and failing to respect them as they are.

This of course, is only part of the story. Respect is not only entailed by the qualities of persons, we must also determine what form that respect should take; taking something seriously is a preparedness to act in relation to it, not blind accommodation.

Care respect, much like *agape*, is attitudinal. To properly care respect is to adopt what is a demanding and self-reflective approach, not discounting our own moral integrity or the universal needs of persons but nevertheless sincerely attempting to see the world through another's eyes. Thus, with regard to religious beliefs, care respect requires that religious

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beliefs are properly recognised as a constituent part of the individual person and their worldview should be acknowledged and responded to as driving deep commitments for that person even where we disagree or believe them mistaken.

A Care respect approach to accommodating religious beliefs thus requires, as a minimum,

- Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.16, 4.1,)
- 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 4.5.2), and
- 3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).

Respect, however, does not entail that anything goes. In the next three chapters I critically explore, through the lens of care respect, the ways that religious beliefs may be accommodated within healthcare. In chapter five, I look at the principles of autonomy and beneficence, in chapter six, the limitations imposed on accommodation and in chapter seven, some problems that arise from attempts to create 'weighting systems' for religious belief. In chapter eight, I construct, using the care respect approach and arguments from chapters five through seven, a new weighting system for accommodating religious belief.

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# 5. Autonomy, beneficence and care respect

In the previous chapter, I identified that a care-respect approach forms the basis of my justification for accommodation of religious beliefs in healthcare. Religious beliefs form an important part of the identity of individual persons. As a result, if we are to properly respect a person, their views must be taken seriously. Indeed, it is the role religions play in people's lives that drives our moral obligation to them, not the fact it is religion, or a particular religion. I suggested a care respect approach to respect for persons was an appropriate way of exploring accommodation of religious beliefs among individually situated persons.

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In this chapter, I will consider two well-known justifications of accommodating religious belief in healthcare, respect for autonomy and beneficence. I begin by identifying some key theoretical approaches to autonomy through liberty and agency, which illustrate the difficulty in finding a single conception of autonomy. I then look more closely at healthcare scenarios in which the religious beliefs of patients may be supported by respect for autonomy or challenged by it. Practical autonomy as advocated by Beauchamp and Childress (2012) focuses on intention, voluntariness and understanding, and does not impose substantive constraints. This type of thinking about capacity to make decisions is emphasised in both ethics and law and underlies 'informed consent/refusal'. I then look at Savulescu and Momeyer's (1997) requirements for a more formal deliberation among patients who want to justify their refusals. Although there are grounds to want a more substantive concept of RfA, requiring it demands unreasonable sophistication from ordinary people, and thus is inadequately respectful of persons as they are. I also consider that in cases of patients waiting for a miracle, even if there were grounds on which they might lack

capacity with regard to understanding the consequences, there are nevertheless other compelling reasons to respect them as persons (Walker 2009).

Concerns about lack of voluntariness and lack of authenticity due to being part of a faith group also challenge acceptance of and accommodation of religious beliefs. Although it would not be appropriate to ignore the risks of manipulation, particularly in light of relational concerns (Stoljar 2000) about forming self-respect (Dillon 1992b), religion is not the sole source, or even the most widespread source of such difficulties. Even though on occasion we might be inclined and justified to intervene, such interventions might themselves reduce someone's autonomy and self-worth (Sjostrand, Helgesson 2008).

Respect for autonomy is unable to meet all of the obligations for care that care respect produces (particularly those that are require a positive obligation). As such, I analyse a second principle, that of beneficence. I argue that beneficence is a duty in healthcare with reference to Pellegrino and Thomasma (1988) among others, and one that extends beyond a biomedical good. I briefly consider three approaches to paternalism (Sjostrand, Helgesson 2008, Varelius 2006, Miller 1981), noting that it generally cannot be justified (though it may occasionally be) under care respect.

I then present a review of the effects of religious belief on patient experience of illness. Generally, this supports accommodating beliefs because of their instrumental role in obtaining beneficent outcomes (although religious beliefs can also produce negative outcomes viz patient wellbeing and health). However, I also illustrate that respecting the patient's belief and accommodating it has a role in caring about the patient in their particularity. Lack of understanding about religious beliefs can directly prevent patients accessing care at all.

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# 5.1 The concept of Autonomy

Like 'person' the concept of 'autonomy' has many potential meanings, definitions and understandings. The extent to which autonomy has been discussed, evaluated, criticised and invoked is, if nothing else, a testimony to the fact we consider it of such importance. Certain things are generally assumed to be associated with autonomy – our ability to act in accordance with our desires (agency), and that others do not dictate or control our actions (liberty). The understanding of autonomy in these various conceptions impacts on what obligations arise from the existence of autonomy in ourselves and others. Unfortunately, the precise natures of neither agency nor liberty are settled.

#### 5.1.1 Liberty

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Berlin (1969) considers liberty as *negative liberty*; to 'be free to the degree to which no man or body of men interferes with my activity' (p. 122), and *positive liberty*; in which 'my life and decisions to depend on myself, not on external forces of whatever kind' (p.131). Negative liberty regards external control as the imposition of constraints on action, so for example, being capriciously detained by the state or having one's movement or expression restricted<sup>56</sup> (MacCallum Jnr 1991, Ringen 2005). The second type of liberty, however, demands a form of self-realisation (Taylor, Charles 2006) and requires the capacity to self-realise to a particular goal. Berlin, however, found positive liberty troublesome (1969). For example, it can lead to people limiting themselves to objectively impoverished, self-abnegating lives in pursuit of

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<sup>&</sup>lt;sup>56</sup> Largely, it is only intentional obstructive acts by others that are considered negative-freedom limiting. Sometimes, this is interpreted as necessitating welfare provisions via positive rights or that internal states might also limit negative liberty.

their aims (Berlin 1969 p.135); inviting coercion in the name of supposed 'liberation' (Gustavsson 2014); and hinging on a presumption of a non-pluralistic value system (Takala 2007).

Some measure of both positive (self-driven) and negative (unhindered) liberty are of value, given that being free to do and capable of doing are generally regarded as important. In other words, when we respect autonomy, it is in part because of the importance we place on freedom. If we did not value negative liberty, it would not make much sense to be concerned with allowing others to do things we disagreed with, and if we did not value positive liberty, then we would not much care what kind of decisions we made about ourselves and each other. The difficulty is in making sure that positive liberty is not interpreted in such a restrictive way that it deprives individuals of their negative freedoms without due justification.

# 5.1.2 Agency

The concept of autonomy is also inextricably related to conceptions of agency, that is, the ability to self-direct through the external world in a manner of one's active choosing, rather than as a passive or instinctive experience. Even absent of external barriers (freedom of action), one could simply exist, so agency (freedom of will) can be considered separate to negative liberty. An agent, then, is someone who is able to make decisions and perform actions that are in agreement with their own desires and motives; and that autonomy is due to deliberating on a course of action that is self-chosen. In healthcare, the course of action will often revolve around opting for a particular treatment at a particular place and time.

Gerald Dworkin (1988, 2014) and Harry G. Frankfurt (1971) had a profound impact on conceptions of autonomy. Autonomous agency stems from the ability to endorse (identify

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with or approve of) one's first order desires, by use of second order desires (a desire to desire the first order desire).<sup>57</sup> They recognise that such decisions should be absent of external or controlling factors (so one does not have agency if one is forced to do something- on threat of death for example). These accounts are generally termed *hierarchical* or *content neutral*. One has autonomy if one endorses a desire and acts on it in accordance with the endorsement.

The philosophical criticism of the hierarchy is threefold;

- One, there could be an infinite regression one's second order desire may come
  from a third order desire, so one has to endorse the second order in light of a third
  order, which may come from a fourth order etc.
- Two, the individual might be manipulated into any one of their desires and volitions,
   which would seem to devalue the choices they made in that they did not seem to
   come from them.
- Three, it seems odd to claim someone is autonomous if their higher order desires
  are not subjected to some kind of rational constraint on what constitutes a reason.

Even extensions of the hierarchical approach to autonomy are incomplete in their resolution of these criticisms. Frankfurt (1992) counters the first criticism by arguing that once someone is satisfied with their second order desires, there is no requirement to endorse endorsements. Other accounts suggest that coherence with ones' other endorsements (Bratman 2003) and coherence with other aspects of the core-self (Ekstrom 1993) serve to prevent the regression problem, but these still fail to address whether one's preferences and

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<sup>&</sup>lt;sup>57</sup> For Watson (Watson 1990), these are constituted by *values*, therefore some recognition of what is *good* is required by the agent. What that good *is*, is left to the agent.

motives can be said to be truly one's own and thus free of manipulation. If there is a need for unmanipulated decision making, then it must in some sense admit of an authenticity only partly gained from cohesion. Some manner of reflection, one not 'directly shaped by rage, drugs, the programmings of a kidnapper, conditions that forbid anything but a narrow range of options and the like' (Christman 2004 p.280) is required. The third problem is sometimes met by what are called substantive theories of autonomy.

Substantive theories can fall into several counts – those which require something of the person's experience, and others which require something of the nature of the beliefs on which one is deciding. For example, there may be agent focused requirements; such as holding certain *value commitments* such as regard for themselves as a morally worthy decision maker; and/or at all stages in the agent's life to have open options from which they may freely choose, called a *procedural independence* (Christman 2004 p.281). Other substantive theories focus on the constraints of rationality, considering that some things are not ordinarily rational to want, such as death or disability (Gert 2006 p.8) or that that holding reasonably true beliefs are a requirement of being autonomous (Savulescu, Momeyer 1997). Wolf (2014) calls for 'the minimally sufficient ability to cognitively and normatively recognise and appreciate the world for what it is'.58

On these accounts, autonomy can be impaired by irrationality, conditioning and the like. If we believe someone is impaired in this way, then our obligation to consider them responsible (and by extension our obligation to refrain from interference) is reduced. However, these ideas presuppose that all beliefs can be objectively seen as true or false, that

<sup>58</sup> She calls this sanity, but it is easily substitutable for 'rationality'. Sanity is problematic word to use,

given some of the examples in chapter 2.

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there is a normative right and wrong that can be identified, and that we can adequately recognise when such an impairment exists. Substantive accounts may be of help in the fair treatment of those who have done criminal acts, or who are very vulnerable, but crucially, it may also be the case that it reduces some of our obligations to those with strong religious-type beliefs in a healthcare scenario.

The involvement of liberty and agency in underpinning autonomy illuminate those things perceived as threats to autonomy. Threats can take the form of external coercion and manipulation by others or a lack of information on which one can base reasoned choices. Immaturity, cognitive impairment, dependency on drugs or alcohol, and heightened emotional states of fear, pain or euphoria might also prevent reasoning.

## 5.2 Religious belief and threats to autonomy

One particular conception of autonomy is all but ubiquitous in healthcare, and that is the (evolving) principle of respect for autonomy (RfA) as advocated by Beauchamp and Childress in *Principles of Biomedical Ethics* (2012, 2003).<sup>59</sup> They offer a 'three condition theory' which begins from a premise that the ordinary choices of persons in day to day life are autonomous, even when they have not reflected on their preferences at a higher level (Beauchamp, Childress 2012 p.103).

For Beauchamp and Childress acts which are autonomous are those which are *intentional*-they 'require plans in the form of representations of the series of events proposed for the execution of an action' (p. 104); show *understanding* – 'an action is not autonomous if the

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 $<sup>^{\</sup>rm 59}$  For some, RfA is 'first among equals' (Gillon, R. 2003).

actor does not adequately understand it' – that is, a substantial, but not full understanding (p. 104); and are *not controlled* 'by external sources or by internal states that rob the person of self-directedness' (p. 104). The day to day decisions of persons should be 'rational' only in the sense they are consistent with someone's life plans (Hope, Tony 2003 p.34).

It is (often) not the person's global competence which is at stake, as one may be competent in some areas and not others. If someone has intentionality, adequate understanding and is not being controlled, then they have capacity<sup>60</sup> to make the decision. If they lack these then they are not. Although the ability to act with intention is binary – one can or one can't vis a particular situation, both understanding and voluntariness exist on a scale, so a threshold of adequate understanding and voluntariness is still required for any particular decision to be made.

There are practical reasons to presume decision making capacity in adults, not least of which is that assessing everyone's capacity for everything would be impossible. Because capacity relates to the ability to understand and retain information as it applies to the person deciding at the time, not to the achievement of 'the right decision', it allows for presumption of competence in those with odd beliefs, despite the psychological tendency of humans to assume that those with culturally odd beliefs are irrational (Gustavsson 2014 p. 279-280). Peculiar beliefs themselves are not an indicator that the patient should, or should not, be automatically considered to have autonomy; Takala warns against privileging certain communities, such as well-known religions, above others (2007 p.227) because of the assumption that less well-known beliefs are less autonomous. Nevertheless, religious

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<sup>&</sup>lt;sup>60</sup> The words competence and capacity are applied differently across fields (law, ethics, medicine) and jurisdictions (US, UK) (Hyslop 2017). I will use capacity as the ability to make an autonomous decision regarding a specific decision, and competence in a more generic way.

(seeming) beliefs can be held in a way that is not of the life-reconciling type (section 4.5.1), and some that seem to be may be the product of delusions (3.5.1). It is unsurprising, then, that particularly unusual or life-threatening beliefs can prompt a closer look at a patient's capacity (Halpern 2012). Therefore, assessment of capacity is conducted with respect to *evidence of incapacity*. Recognising some decisions have greater consequences than others, Beauchamp and Childress apply a sliding standard to evidence -for example, one need not make such in depth inquiries of the patient to take a blood sample, as one would expect if they refused life-saving care (Beauchamp, Childress 2012 p.120).

It would not be, after all, ethically required (and in fact, may be ethically prohibited) to rely on the contemporaneous wishes of a patient unable to make self-regarding decisions because of an inability to form life plans, weigh up or retain information. Treatment can ethically, and legally (*Mental Capacity Act.* 2005) be done (or withheld) in the best medical interests of those who cannot yet, or currently, decide for themselves<sup>62</sup> (Westra, Willems et al. 2009, Macklin 1999, Oshana 2001). Where possible, these actions are carried out in order to restore autonomy – as much as is possible (Beauchamp, Childress 2012 p.107)- and for the

sake of another important healthcare value, beneficence.

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<sup>&</sup>lt;sup>61</sup> Religion is also experiential and emotional (2.1.5), and for reasons of space I have not discussed the growing literature on the part emotion plays in decision making as the challenges generally seen to be posed by religious beliefs relate to belief formation and to voluntariness

<sup>&</sup>lt;sup>62</sup> RfA extends only so far as decisions made with respect to the patient, by the patient. As such, it imposes a reasonable limit in that a decision motivated by religious belief on *behalf of someone else* (such as a child or incompetent adult) is not ethically compelling. This and other limits on accommodation are discussed in the next chapter. RfA is also subject to a multitude of cultural interpretations, but I do not develop this further in the thesis.

#### 5.2.1 Religious belief and the rationality of deciding

Hyslop (2017) recognises that decision making capacity is generally seen as a matter of the *process* of using and weighting information. In this way, we can consider that a decision-making scenario looks like this; The patient has disease D, personal values/lifeplans V1, V2 etc, and the medical options are a variety of treatments X, Y, Z, in which one is preferred by the professional in charge of their care as being most likely to improve or cure D. In a process account, provided the patient accepts D and understands (in general terms) the nature of X, Y and Z, a patient will use their values and circumstances to decide which option they want. In the matter of weighing the information, the patient decides how important each variable is to them.

Usually, the patient puts most weight on 'getting better' and choses whichever of X, Y and Z is most likely to lead to getting better, with least negative consequences (side effects, loss of social or financial resources for example). Because the HCP can only really know what presents the best *medical* option, other values such as 'how much mental confusion would be tolerable for how much pain relief are a matter for the patient to decide. Of course, to decide on this, the patient would need to know how treatment or non-treatment would affect their day to day life, necessitating tailored, particular information giving. This places an obligation on providers to give this information.

Consider, for example, that an organ transplant is both the least expensive and most beneficial treatment for kidney failure. Presented with the reality of fatal kidney failure (D), many people would prioritise (give most weight to) the most effective treatment. Paul in my example (3.8.1), refuses the recommended treatment because he gives more weight to his belief that taking another's life essence into the body will have serious metaphysical

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consequences.<sup>63</sup> Paul also has a V about getting better, but it is being overridden by V about the consequences of his actions.<sup>64</sup>

Generally, then, capacity in decision making is considered as the ability of the individual to weigh up the options in a medical decision according to *their own* values and beliefs. Such a capacity rests on a *process* (Freedman 1981) of 'internal rationality' (Charland 2001). If V were true, it would make absolute sense to refuse treatment X because of the consequences. On this account, religious beliefs that lead to refusals (at least) should be accepted, provided the patient is able to perform such a process.

Savulescu and Momeyer (1997) argue, however, that internal rationality requires some constraints more than simply prioritising values. They state:

It is rational for a person to believe some proposition if he/she ought to believe that proposition if he/she were deliberating rationally about the evidence available and his/her present beliefs, and those beliefs are not themselves irrational (Savulescu, Momeyer 1997 p.283).

Even allowing that religious beliefs might be 'rationally allowed', Savulescu and Momeyer ask for internal reasoning to contain a solid and theoretical understanding of what represents a reasonable/true belief to be appropriately autonomous. The person

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<sup>&</sup>lt;sup>63</sup> A more familiar example of a V belief might be that having a blood transfusion denies one access to a heavenly life after death.

<sup>&</sup>lt;sup>64</sup> In my example, Paul's belief about metaphysical consequences is derived from a fundamentally unverifiable religious standpoint. Secular medical practice is committed to these beliefs not being true (otherwise, practitioners of medicine would be committing abhorrent acts)

<sup>65</sup> Interestingly, the weight leant to communities in the weighting process (see chapter seven) seems to look for coherencies both between beliefs and between belief and action – although the danger in looking to communities for consistency is to discount the individual.

'deliberating rationally' is responsive to evidence for their beliefs, examines beliefs for consistency, and exposes their reasoning to the norms of logic. If one is to base a decision on their beliefs and ask others to go along with it, then they should care enough about those beliefs to analyse them properly – refusing to do so might constitute an autonomy-limiting wilful ignorance (Savulescu, Momeyer 1997).

For Savulescu and Momeyer, JW's ought to be challenged to justify holding the belief that transfusions are forbidden over a less restrictive one. For example, the existence of dissenters from the blood refusal policy (Muramoto 1998) and its change over time, should be considered by the patient as evidence against the rule being as *certain* as it is. The same consideration, extended to Paul the Druid, would be to argue that other Druids do not, or need not, hold by this rule, or similarly to Katy regarding Wicca (3.8.2). Thus, according to Savulescu & Momeyer (1997), a physician is justified in challenging the patient on whether beliefs about the rules are true. Savulescu and Momeyer agree that the time for doctors to be involved in this activity isn't in an emergency situation. Nevertheless it should be a responsibility for physicians to encourage this type of thinking in their patients as 'to do any less is to abandon patients to autonomy-destroying theoretical irrationality' (p. 288).

This account poses several problems for religious belief-based decision making. Firstly, if someone simply assigns weights to various values because of their religious belief, it is not clear that this is the province of irrationality. Secondly, the request leads to *extensive* rationalising within -and indeed between- all religions. This is a task that large religions often leave to their theologians, rather than individuals (Bock 2008). Bock notes that people trust their religious leaders in much the same way that scientists take on trust that the credentials and reasoning of other scientists are good reasons to believe what other scientists say is true. I return to this point in chapter seven. Thirdly, it allows a clinician to

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privilege *their* (privileged) version of rationality onto a patient, presupposing that this should and will make sense to people with a fundamentally different worldview and life experience. To insist on the reasoning Savulescu wants, would be to abandon particular patient-persons in the name of rationality. Doctors themselves are not all atheists or strict rationalists, and nor is it clearly appropriate for them to impose an unnecessarily limiting gatekeeping judgement on the patient's beliefs. The methods that people use to place one or another belief over another, and the weight they give particular things, are an integral part of their worldview and thus of the very particularity we ought to respect.<sup>66</sup>

Questions about the rationality of religion and religious beliefs stem, in part, from the familiarity that ethicists have with critical thinking and argument rigour. Most people, religious or not, do not have such a habit of meticulous critical thinking and yet are able to live comfortable, successful and acceptably moral lives. A 'rational' process does not favour patients who are not traditionally considered good at reasoning (for example women, see section 4.3), those who are not practiced at articulating and defending their reasoning, or those who believe that faith is beyond conventional reason (Bock 2008). It is not appropriate to confer autonomy only to an elite few who can meet an idealised form (Hyun 2001 p.199) rather than the bulk of human beings who live their lives in the messy reality of actual existence.

A care respect approach to religious belief has to consider the realities of the individual's life in the *now*. Whereas it may be an ideal to increase critical thinking among people in general, because ignorance of verifiable facts causes a lot of hurt, it is not currently achievable within

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<sup>&</sup>lt;sup>66</sup> Some decisions *are* irrational – perhaps those caused by phobia, for example- which prompt Culver and Gert to argue it is necessary to identify irrationality (Culver, Gert 1987, Gert 2004). Accepting what a chosen authority says is part of a worldview in a way that *phobia* of a procedure is not.

health care consultations. HCPs have limited time and usually do not have the in-depth knowledge of the individual's religious, or other, beliefs required to do so appropriately (Bock 2008, Orr, Genesen 1997). <sup>67</sup>

#### 5.2.2 Rationality and miracles

3690 A particular difficulty arises with the question of miracles or 'special exceptions'. Not all religions accept that miracles can occur, and fewer support the idea that one can be asked for or expected. Belief in miracles is also not only the preserve of the religious, as against the odds recoveries are reported occasionally (perhaps due to mis-diagnosis or a failure to understand the importance of some unexamined factor).<sup>68</sup> However, waiting for a miracle (thus eschewing a particular treatment, or maintaining 'futile' measures) is something that is reported in health care ethics literature, including a special feature of the American Journal of Bioethics in 2018 (Orr, Genesen 1997, Clarke 2000, Sulmasy 2006, Bibler, Shinall et al. 2018). Miracles pose a specific problem for the idea of respecting autonomy, even one based on a sufficient understanding requirement. A patient may otherwise have sufficient 3700 understanding and adequate capacity to make a medical decision but their belief that their deity (or other force) will intercede on their behalf seems to prevent them from understanding that the probabilities apply to them. If a patient's ability to assign weights is itself compromised by the expectation of a miracle, perhaps they are not autonomous

(Martin 2007, Walker 2009).

 $<sup>^{67}</sup>$  Some authors have suggested the use of 'religious interpreters' to overcome this problem and I discuss this in chapter seven and eight.

<sup>&</sup>lt;sup>68</sup> This is David Hume's point in his *Enquiries Concerning Human Understanding* (Hume 1975, 'Of Miracles'). The probability of something being a 'miracle' against the probability of some flawed observation or other natural event producing them is such that we cannot rationally believe in miracles.

However, understanding and perception of statistics and risks in general is poor (Royal Statistics Society 2013). The perception and assumption that people always respond in an abstractly rational and prudential way to information is mistaken; something which has been recognised in the statistics and social policy literature for some time (Kemshall 2014). The demand to understand and weigh statistical facts thus seems to expect a standard of probability assessment which is beyond that found in the general population, returning us to the concern that we are simply asking too much of ordinary people.

Importantly, what is at stake in determining the course of action in the miracle case might be the outcome of other areas of the patient's care – for example, whether they can gain access to hospice care whilst in 'denial' or retain access to other treatments. For example, Sulmasy (2006) reports a case of a man who could not be admitted to a hospice for terminal care because he was not deemed as 'accepting' his death. In other cases, forced treatment may be considered acceptable (*DH v PS*, EWHC 1217 (Fam) [2010]).

Although their decisions may be irrational and nonautonomous, determining whether to abide by the decisions of (generally) autonomous persons is independent of an assessment of whether the decisions themselves are autonomous (Walker p 355). Other factors related to the person, such as avoiding invasive and unwanted treatment of one's body are crucial. Even if the decision is irrational because of an inability to apply the statistics, respect for the person might well still prevent an overriding of their decision.

### 5.2.3 Religious belief, voluntariness and authenticity

The second challenge faced by people with religious beliefs in healthcare relates to voluntariness and the authenticity of their beliefs. As I indicated in the previous chapter, we are all inexorably shaped by our experiences and relationships with other people, thus it is

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wrong to assume that any set of circumstances in which decision making is less than ideal constitutes autonomy compromising influence. Beauchamp and Childress express this by stating that not all influences are controlling (2012 p.104). However, some pressures are perceived as particularly problematic for autonomy viz religious beliefs, such as aggressive members of the same religious sect or 'brainwashing'. In light of this it is generally the case that patients' decisions should be voluntary and authentic.

Voluntariness is the requirement that the patient (usually in the case of giving or refusing consent) does so of their own current volition, absent of coercive threats (not absent of persuasive argument or recommendation). As religious groups can be very vocal in explaining the moral imperative (and the consequences of breaking certain moral rules) to adherents, so perception is often high that those with religious beliefs are under greater pressure to decide in line with the groups' belief, rather than their own wants. Authenticity, however, is whether the individual has had sufficient *historical* freedom and opportunity to formulate their own values, as suggested by Feinberg (1989), who states 'A person is authentic to the extent that ... he can and does subject his opinions and tastes to rational scrutiny... he can and does alter his convictions for reasons of his own' (p.33).

Hyun (2002) expresses concern that 'some patients' values might not be authentic for them, in the sense of being free of coercive formative influences' (p. 15). A requirement for people to have been free to form their own beliefs is an 'authenticity condition' of individual autonomy. However, as all humans have been reared by other humans, they inevitably are shaped by and in response to others. A more credible version of authenticity is whether the person has had a genuine opportunity to see and explore alternatives, but it is not clear that this, like extensive rationality requirements, would be necessary for autonomy in medical

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decision making. Feinberg himself comments that to expect someone to be completely selfmade is self-defeating and impossible;

to conceive of authenticity in such an exalted way that its criteria can never be satisfied ... If we take authenticity to require that all principles (beliefs, preferences, etc.) are together to be examined afresh in the light of reason on each occasion for decision, then nothing resembling rational reflection can ever get started (Feinberg 1989 p.33).

A person is who they are now, and to deny them what authority they currently have because they have had a particular type of past, is to again exclude ordinary people from control over their lives. It might be morally desirable that people develop authentic senses of their identity and values, but that is not equivalent to their having less value now.

A patient who is not generally particularly devout but suddenly refuses or demands treatment after a visit from a religious leader or devout relative might be deciding involuntarily. One who has never examined their beliefs in any way, by contrast, is possibly behaving inauthentically. However, within a care respect approach, understanding the patient in their entirety is necessary. Finding religious beliefs during illness is sometimes referred to 'foxhole religion' in a negative way (after the battlefield expression 'there are no atheists in a foxhole'). It is important to remember that one of the times that people are most likely to find religious belief of relevance is when confronted by the adversity of injury and disease. It is not automatically inauthentic or a sign of coercion for an individual patient to pay more attention to their religious beliefs at such a time (Beauchamp, Childress 2012 p.103). As Takala comments, '[m]ost decisions are also value judgments about what people see as valuable to them in their current situations. And in these decisions the doctor holds no special expertise' (2007 p.227).

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#### 5.2.4 Coherence and consistency

It is common to examine 'odd' beliefs in relation to whether others hold the same belief, whether a particular belief fits in with other beliefs in the patient's worldview, and whether the patient has suddenly adopted it (in such a way as it is not a stable volition). The last of these points has been considered above – people give different weights to different things according to what is most valuable to them at the time. Whereas inconsistency may be a sign of coercion, it is not necessarily so. However, both internal and external agreement are presented as important for recognising incapacity. As noted above, coherence is a feature of some accounts of autonomy (Bratman 2003, Ekstrom 1993).

A lack of agreement with others seems to reflect Savulescu and Momeyer's (1997) requirements. I am reliably informed by medical colleagues that if others and groups of others hold a particular view it is considered less likely to be irrational or delusional than when it is held by a single person or very small group. However this is why Takala (2007 p.227) cautions against privileging large religions – both because large religions can still be autonomy threatening, and because small ones need not be. The particularity of care respect, and the importance of individual identity are counters against why this shared belief should be given such attention. In chapter seven I return to this issue in evaluating multifactored ways of assessing beliefs.

When a belief seems odd, unusual and bizarre, it seems almost intuitively to matter that it reflects other, similar, beliefs and desires, rather than being random. Partly, this seems to be as a way of finding beliefs that have been recently imposed and may be inauthentic or non-voluntary, which can be viewed in light of the appeal to voluntariness and authenticity above. Partly, though, it seems to be a recognition that something of the nature of beliefs that we are obliged to take seriously is the way in which they integrate into someone's life-

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plan. Beliefs support each other in a worldview (2.1.5), and one is more likely to hold beliefs in an important way if they are held up by other beliefs. Nevertheless, having conflicting beliefs, values and ends is not irrational. There are good reasons not to give internal coherence too much authority – the intersectional nature of identities for example, would not rule out a woman from being both a catholic and a queer feminist (Aldridge 2013 p.177, Currans, Wilcox 2004). Overdemanding coherence requirements is simply another way of expecting everyone to have engaged in rationalising towards a reflective equilibrium.

#### 5.2.5 Relational autonomy and second persons

In the previous chapter I described some feminist criticisms of moral philosophy that had led to an ethics of care. *Relational autonomy* is another concept that arises from feminist critiques; the conception of autonomy as atomistic and self-reliant is replaced by a recognition that autonomy cannot happen without relationships. As Sheila McLean (2009) comments 'we are virtually never free from external influences, yet we nonetheless generally expect and receive respect for our actions (and inactions) outside of the healthcare context. Totally free will, then, is aspirational rather than practical' (p.51).

Rather than a simple focus on formal rationality and information on 'options', relational autonomy considers a need for a decision making that expressly considers other values besides rationality, such as feelings, self –respect, the ability to relate oneself to others and the ability to reflect on the sources of one's reactions. Concepts of relational autonomy, however, highlight a tension found in feminist ethics between advocating caring and ignoring the value to women of being seen as fully autonomous beings.

The paradigm example of someone with autonomy is the white, relatively healthy, middle class male (Donchin 2000). This is an individual who is 'self-sufficient, independent and

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self-reliant' (Code 1987b p.358) and 'under constant threat from other (equally self-serving) individuals'. Thus, criteria for being autonomous are based on the decisions this idealised figure might make, judging others against the self, akin to arrogant perception (Frye 1983 and section 4.4). From this perspective, the decisions that might be made by those who are dependent in some way, for example women, people of colour and people with medical conditions or disabilities are disvalued (Sherwin 1992, Dodds 2000). Conventionally, autonomy values independence and freedom from interference and accordingly devalues dependence on others to the level of moral failure or personal weakness (after all, such dependence is a threat to autonomy). Individuality becomes indistinct from individualism. It may be more helpful to think of ourselves as 'second persons' (Baier 1985 p.84, Code 1987b). Instead of the conventional independence envisioned in the atomistic ideal thinker, people become who they are -and continually change and develop as persons- in response other people. Code (1987b) does not consider care a replacement for rules/justice/impartiality, or 'deny the achievement of autonomy a central place amongst feminist goals' (p. 358) but she considers that an 'autonomy obsession' serves no-ones' purpose well. An idealised autonomous person leads an impoverished, impersonal, isolated life. By thinking of ourselves as second persons, we recognise our valuable uniqueness grows out of interdependence and we 'continually turn back to it for affirmation and continuation'

There is considerable appeal in extending the concept of autonomy to include interdependence, even though the 'conventional' reading is often unfairly portrayed as narrower than it might be. Autonomy does not require us to be isolated; May (2005 p.307) for example, considers that an autonomous person is best thought of as a helmsman who steers their own life and may rely upon both others' authority and assistance in doing so. It

(Code 1987b p.361).

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is true that sometimes the persons we are reflect *harms* inflicted on us by others, but we are enriched as persons by the *goods* given to us. A more relational form of autonomy, then, engenders respect for the individual situated within the complex of relationships and other factors; a complex of relationships that can include divinities and faith groups.

However, a key element of being a *relational* moral agent is that one is able to reflect on how their decision making is shaped by power (and other) relationships with others (Stoljar 2000 p.95, Dodds 2000), particularly regarding seeing themselves as capable and entitled to make such choices (Dillon 1992b). Stoljar argues that as a result, some substantive element to autonomy is required (Stoljar 2000 p.95) in order to protect persons from oppressive norms (pp. 98-99). From this, it seems that perhaps someone should step in and present details for a patient to challenge their beliefs with (Savulescu, Momeyer 1997), over and above the standard choice-making approach to autonomy, because the individual may never have been able to think of themselves as morally relevant. Understanding that the religious believer might have been socialised into their beliefs and been denied opportunity to live their life in another way, could count as a factor for disallowing their decisions, inasmuch as their ability to critically self-reflect and value their own judgements may have been damaged by their relationships with others. Positive obligations of supporting people's autonomy, beyond providing facts about treatments and diseases, are part of a care respect account.

However, it is far from clear that such a thing should actually happen in clinical encounters, that a rationalist epistemic approach is always appropriate, or that doctors and consultants should be the ones to do it. Returning to concerns about liberty, Gustavsson comments:

we open ourselves up to the disturbing possibility of dismissing other people's current will as irrelevant to their freedom. If we already want to

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hinder them politically from acting in line with their actual, empirical wishes, for the sake of some other goal that we believe is more important, we now risk going even further, concluding that by doing so we would not even be coercing them, but rather liberating them from themselves (Gustavsson 2014 p.282).

A care respect conception of autonomy would recognise that if someone lacks the self-worth to make medical decisions for themselves, something is limiting their autonomy, but that this need not mean they should be forced into a particular mode of thinking or compliance over a specific decision. However, extensive requirements for reflectiveness, as discussed above, ask too much of ordinary people. Additionally, if we do intervene, we are continuing to limit someone's ability to influence their life, and potentially ostracising them from something they value. Such an action can, of itself, be damaging to the individual's self-esteem, further convincing them of their inability to make decisions. A judgement about whether the person is making the *right sort* of decision should remain a decision we should be extremely cautious of making.

To be properly relational, autonomy must be particular, and address not only the nature of the patient, the provider and their relationship, but that of the entire health institution. Such an extensive critique is well beyond this thesis.

## 5.2.6 The legal position in brief

ethical consequences. If a capacitated person refuses consent, but such refusal is overridden, the medical staff or healthcare organisation involved risk criminal prosecution. If

the patient lacks capacity, then essentially the medical staff may proceed under reasonable

When doctors and patients clash over refusal of treatment, there may be legal as well as

grounds in the patient's interest. Statutes and case laws have thus been developed to protect the interests of patients, healthcare providers and the public, generating the current medico-legal system. Unsurprisingly, much of the legal framework around autonomy relates to issues of capacity.

The principles of the Mental Capacity Act 2005 state that 'a person must be assumed to have capacity unless it is established that he lacks capacity, and that '[a] person is not to be treated as unable to make a decision merely because he makes an unwise decision.' (*Mental Capacity Act.* 2005 C9, 1.1) and

a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means) (*Mental Capacity Act.* 2005, Section 3).

The MCA developed from significant pre-existing case law. Case law established the right of autonomous adults to decide unwisely or irrationally regarding medical treatment. In particular, *Re C* (*Adult: Refusal of Treatment.* 1 All ER 819 [1994]) set an enduring standard whereby an adult has capacity to consent or refuse so long as they can understand and retain the information relevant to the decision in question, believe that information, and weigh that information in the balance to arrive at a choice. C suffered from paranoid schizophrenia and had developed life threatening gangrene. He repeatedly refused to consent to an

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amputation. The hospital argued that C's capacity was impaired by the schizophrenia. The court found that although C's general capacity had been impaired, there was insufficient evidence to establish a lack of sufficient understanding of the nature, purpose and effects of the proposed treatment, C had understood and retained the relevant information, believed it, weighed it, and had arrived at a clear choice. C was determined to be able to refuse.<sup>69</sup>

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The example in Re C was tested again in 1997 in Re MB (An Adult: Medical Treatment [1997] 2FLR 426). In MB, a patient refused a caesarean section due to a fear of needles. In Re MB, her needle phobia was determined to be compromising her capacity, and thus it was ruled it would be acceptable to administer the anaesthetic by force. Butler-Sloss took the opportunity to reiterate capacity; subsuming the 'belief' component of Re C into understanding and retaining.<sup>70</sup> It is arguable that MB, like C, was able to understand, retain and arrive at a decision, suggesting some inequity in how the cases were resolved. However, considering cases around the treatment of Anorexia Nervosa (e.g. *Re KB* (Adult) (Mental patient: medical treatment) [1994] 19 BMLR 144) where the inability to override the impulse not to eat is part of the condition, suggest that the differentiation is that MB's refusal was directly connected and due to her phobia, whereas C's was not related to his schizophrenia. (Cherkassky p.189). In short, there needs to be evidence that in some way the patient cannot

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<sup>&</sup>lt;sup>69</sup> Other examples include:

<sup>[</sup>T]he patient is entitled to reject [the] advice for reasons which are rational, or irrational, or for no reason (Sidaway v Board of Governors of the Bethlem Royal Hospital [1985] AC 871);

<sup>[</sup>a] patient's interest consists of his right to self-determination – his own life how he wishes, even if it will damage his health or premature death (Re T, 9 BMLR 46 [1992].

if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even....though they do not consider it to be in his best interests to do so... (Bland, AC 789 [1993])

 $<sup>^{70}</sup>$  Justice Munby in Local authority X v M [2007] EWHC 2003 sees this as laying the foundation of the MCA definition

understand or adequately evaluate the medical condition, proposed treatment and consequences.

The question of religious beliefs in particular has been raised several times. In Re MB (although not a case involving religious beliefs) Butler-Sloss states:

a competent woman who has the capacity to decide may, for religious reasons, other reasons, for rational or irrational reasons or for no reason at all, choose not to have medical intervention, even though the consequence may be death or serious handicap of the child she bears, or her own death (Re MB (Medical Treatment) [1997] 2 FLR 426 (CA)).

In *re S* (Adult: refusal of treatment) [1992] 4 all ER 671, a pregnant patient underwent an emergency caesarean section which they had refused for religious reasons. Brown P made a declaration for surgery because both mother and baby would die within minutes if surgery did not go ahead.

S appealed after the fact and it was held that the procedure had been a trespass to her person. Judge LJ states:

She is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of their unborn child depends on it. Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant (Judge LJ, St George's healthcare NHS trust v S [1999] Fam 26).

However, capacity may be compromised by others, as in *re T*, where Lord Donaldson observes that a tired, pained patient in a close relationship with someone persuading them to refuse may result in the patient being overborne by a will not her own. Lord Donaldson 184

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notes that persuasion based on religious belief is compelling, particularly if bought to bear by a close relative on a worn-down patient. So, religious beliefs are not a sign of incapacity per se under the law, but the religious beliefs which are legally respected in terms of making decisions must be the patient's own.

Thus, legally, a patient is able to make a choice which is unwise, unreasonable, or morally disturbing provided that they are able to understand, retain and weigh up relevant information. If the patient has a condition which prevents them from doing so by being substantially interwoven with the decision, they may be overruled, even where they – on the face of it- appear to meet the understanding, retaining and weighing criteria.

# 5.3 Beneficence: doing good in medical ethics

Although respect for autonomy might allow Paul and Katy (2.8) to refuse treatment, and oblige the disclosure of information about the medication and treatment to Katy, it would not require them to be given alternatives. This seems to contravene some important sense of caring for them. An important part of care respect is *to* care *for*, to take on some of the other's ends as one's own (for example, to assist in healing and to alleviate pain), to be involving in caring activities towards that person. Beneficence, the concept of doing good for someone, seems to fit naturally with this obligation.

Beneficence is probably most familiar as one of the *four principles* (Beauchamp, Childress 2012). Beauchamp and Childress (2012 p.203) identify three inter-related concepts – *beneficence*, an action done to benefit others, *benevolence*, the character trait of being disposed to act beneficently, and the *Principle of Beneficence*, a moral obligation to act beneficently.

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Unlike respect for autonomy (and non-maleficence), which largely involve basic obligations of non-interference and place only limited positive requirements (in the case of RfA and disclosure of information for example), a principle of beneficence *demands* more extensive positive action.

Some form of stipulation to be helpful to others exists in common morality and in ethical theory. Hume, for example, claims that 'nothing can bestow more merit on any human creature than the sentiment of benevolence in an eminent degree' (Hume 1777 II.II). Utilitarianism's central core is also arguably beneficent, in maximising the greatest happiness for the greatest number. In deontology, despite the classical conception of respect being about not using rational-others solely as means to our ends, Kant (1779) recognises the importance of fostering other people's ends in his duty of love '[t]he duty of love is the duty to make the ends of others my own, the duty of respect is the duty to not degrade others to the status of mere means to my ends' (6: 449–450).

On beneficence, Kant argued that there need be no limit on the *scope* of benevolence from inclination, but that the duty of beneficence – that which we were obliged to do- could not be unlimited or applicable at all times. Thus, it was a duty nevertheless, but an imperfect one (Hill 1993). Gert (2006) argues that there are no moral rules of beneficence, only moral *ideals* of beneficence, beneficence therefore being a supererogatory matter wherein beneficent acts are both acceptable and laudable, but not a requirement. Imposing a moral obligation to help others would put the individual under impossible strain – 'No one can impartially follow moral ideals all of the time. Indeed, it is humanly impossible simply to follow them all time, because everyone needs to sleep sometimes' (Gert 2006 p.43).

Under Gert's principles, we are not ever obliged to help others – it cannot be part of an ethical minimum to do so, although it may be praiseworthy if we do. Some ethicists, like

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Singer (2011, 2010) for example, do advocate for just such a highly demanding utilitarian duty in day to day life. Beauchamp and Childress also argue that there is a duty of beneficence, but that it is an *imperfect* one - there is not always a duty to do a particular action, but that there is nevertheless always a level of beneficence that is required. We can always refrain, they argue, from harming others (making non-maleficence a perfect duty,) <sup>71</sup> but cannot do good to all persons at all times (Beauchamp, Childress 2009 p.168).

Concepts such as care ethics do not have such immediate difficulties with the idea of beneficence or benevolence. These concepts are built around relationships in which there is a recognition of unequal needs, an intrinsic obligation to care for and about someone else, and to help them realise their ends (Dillon 1992a p.116). *Care*, however, is not directly synonymous with *beneficence*. Both lead to -or are aimed at- producing a benefit for another person, and as such in order to care one must aim at a beneficent result. However, a principle of beneficence requires no emotional predisposition (benevolence) or particularism, whereas care, even in its care-respect formulation, does make such a demand. A nurse can care for someone admirably well, even if they do not care about them as an individual; even a limited, specified, imperfect duty of beneficence does not ask for a predisposition to take positive steps to serve another's ends.

Nevertheless, aside from the remit of *general* morality, there is good reason to consider that a duty of beneficence exists within medicine, even if it does not exist in any clear way outside of it.<sup>72</sup> The care and welfare of patients is the primary concern in the professional codes of

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<sup>&</sup>lt;sup>71</sup> Cutting into someone, as a medical procedure, inevitably does cause a harm (associated consequences of pain and recovery) but it's a harm that is justified for the good it brings about and the greater harm avoided.

<sup>&</sup>lt;sup>72</sup> Those formulating ethical theories based on parent-child or friendship relationships would consider a duty of beneficence to be as natural and normal (if not more so) than the rational-equals basis of general morality.

all health professions (General Medical Council 2013, General Pharmaceutical Council 2017, Nursing and Midwifery Council 2015, Chartered Society of Physiotherapy 2011, General Dental Council 2013). The values of medicine include not only respect, but traits such as compassion, benevolence (Patterson, Prescott-Clements et al. 2016 p.860), humanity and kindness (NHS 2015). The presence of a requirement for respect, humanity and kindness within the NHS constitution shows beneficent actions are considered to be crucial to healthcare and will be expected by patients.

In their Principles, Beauchamp and Childress argue (2009 p.168) for a specific obligation of beneficence towards patients – the alleviation of pain and suffering, the saving of lives being among the ends of medicine itself. Because helping others is a professional duty in healthcare, and because 'Do your Duty' is one of Gert's moral rules, there can be agreement that beneficence is an obligatory part of healthcare ethics.

Beneficence, therefore, cannot be considered supererogatory within medicine. However, even within medicine it remains a general principle, that we cannot be obliged to do what is not possible (a health professional cannot hold back death for ever, or provide something that does not exist) but we are nevertheless obliged to do what we can. This entails, of course, that thought and effort are put into making it possible, not discounting the options out of hand. Thus, beneficence offers legitimate support to accommodating religious beliefs, provided that accommodating those beliefs furthers those beneficent ends.

# 5.3.1 Health, welfare and wellbeing – what is the good in doing good for someone?

There are several ways of thinking about 'the good of the patient'. This is most easily recognisable in the form of healing an injury or diseased body so the patient recovers in a

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functional state. As medical technology has developed, the alleviation of pain and suffering during this process has also become a recognised element of medicine, such that raw survival is not the only, and sometimes not at all, the most desirable outcome.<sup>73</sup> For example, virtue ethicists Pellegrino and Thomasma consider that 'the good of the patient,' is *the* end of medicine (Hoyt-O'Connor 1999). Autonomy becomes one of the goods of the patient, 'part of the goal of treatment, one of the goods of the patient, to be promoted but not to the total exclusion of all other goods' (Pellegrino, Thomasma 1987 p.31). A 'right and good healing action' deals with the physical aspect first (Pellegrino, Thomasma 1988 p.117), but these goods include 'the good as perceived by the patient, the good of that patient as a human being' and importantly, when considering issues of religious belief, the 'good which transcends our good as human and, hence, which pertains to our spiritual destiny' (pp.117-118).

There are a range of non-clinical activities that contribute to the welfare of a patient, including emotional support and comfort, information signposting, nourishment, toileting and hygiene. This applies not only to patients who can be physically cured, but to patients with mental health conditions, those undergoing a non-disease process such as pregnancy or childbirth, and those with chronic or terminal conditions that cannot be cured. The concern of those working in health care legitimately – and I believe essentially – features these other areas beyond the disease or injury directly. As such, beneficence as obligatory in healthcare extends beyond acts to restore biomedical functioning. Any role that religious beliefs play cannot only be measured in terms of physical recovery and pain relief, but where

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<sup>&</sup>lt;sup>73</sup> The ability to perform treatments that are not required for life saving – aesthetic cosmetic surgery as an example- forces questions about whether treatment of this type is beneficent and is merely transactional (or non-maleficent) is something I am unable to go into here. Likewise, I am putting aside issues of preventative medicine or medical enhancements.

they fit in the ends of supporting autonomy, easing sadness, nurturing and protecting. The NHS Constitution itself emphasizes the values of giving comfort and relieving suffering (NHS 2015). Suffering, in this case, and as emphasised by the hospice movement, is not equivalent to pain, and may encompass mental distress, other bodily symptoms, existential/spiritual crisis and fear (Terry, Olson 2004).

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It is possible to adopt an extremely broad account of what health is, and the wider the account of health, the more demanding a normative beneficence becomes. The World Health Organisation (WHO) calls health 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (World Health Organisation 2018). This WHO definition is perhaps too broad and idealistic. Many people consider themselves to be healthy even with some manner of disease or infirmity – consider paralympic athletes, for example. The requirement for 'complete' well-being is considered implausible given the variability of disease and ageing populations with chronic disease (Huber, Knottnerus et al. 2011). Additionally, to achieve the WHO's aims, there may need to be change in social and political structures beyond easy reach of day to day healthcare practice (although I consider this demand to be a strength of a broad definition). Other conceptions exist, such as the ability to adapt (Huber, Knottnerus et al. 2011) or as foundational building blocks for autonomy and self-determination (Seedhouse 2001). In either case, health care requires more than the alleviation of an organic illness.

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Even if one wants to restrict the definition of health to a broadly biomedical good, the meeting of non-medical needs (such as taking account of religious requirements) of the patient can also directly or indirectly support the 'medical' good. A patient that is unable to eat hospital food or take normal medications because of religious restrictions, or is isolated from their support structures, will not do well. A treatment plan that neglects to include key

elements of the patient's life will not achieve its beneficent aim if the patient is not motivated to follow it. To consider accommodation of religious belief as a means to achieve a better outcome is to see it as instrumentally beneficent. However, this may fall somewhat short of the demand of care-respect – to be benevolent and to actively and emotionally care.

#### 5.3.2 Paternalism

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Tension between autonomy and beneficence can be seen in the concept of paternalism. In paternalism, the health professional believes – and may have good evidence – that the patient's freely chosen and informed decision will result in a bad outcome for the patient. This may be in the increase of pain and suffering which was avoidable, or to the extent of the patient choosing death – apparently the very opposite of health. After all, if HCPs are serious about doing good, then how could permitting patients to die, even when the patient choses to do so rather than accept care, be beneficent?

Occasionally, concerns about paternalism are met by indicating that autonomy itself can be at the root of paternalistic decisions. If a patient's decision seems to be on the limits of autonomy, coerced, non-voluntary or inauthentic, then interference in a patient's decision could be justified to secure them further autonomy. Varelius suggests that what is key is not that autonomy is intrinsically valuable (indeed he argues that it is not, and when it is not in service of the patient's wellbeing, it is not the primary concern) but that what is often at stake is a difference between what the patient values as a good and what the medical professionals do (Varelius 2006 p.385). This is an important consideration. Care respect does not rule out actions that could be paternalistic, nor would it rule out a patient deferring to the expertise of others, but it would require that the patient's own values, integral as they are to the individual themselves, be at the heart of consideration. If the patient is able to

191

explain that, because of her values, her decision matters more than the negative consequences, then even an autonomy-limiting and not obviously beneficent outcome could be accommodated. In my examples, both Katy and Paul (3.8) are facing negative consequences from their actions, death and severe scarring respectively. Both have indicated that their motivation to accept the consequences comes from a place of deep meaning. It would not be respectful of the persons they are to force treatment. Neither would it be practical.

Miller (1981) for example, suggests that a patient refusing care, when they have previously been well adjusted to their condition, might not be acting authentically due to despair or self-doubt. Restoring capacity and decision-making competence in those who seem to lack it is considered a legitimate aim of medicine, where to do so is part of restoring normal functioning. In Miller's example, it is not the absolute capacity for decision making that is relevant, but that the patient seems to be acting out of character – with less autonomy than they might otherwise do.

Paul (3.8.1) has a long-standing history of refusal type behaviour, so this example seems ill fitting in his case. In Katy's case (3.8.2), it is less clear if she is experiencing despair, but self-doubt seems a fair consideration. Nevertheless, this would only be an opportunity for the staff to further enquire, not make assumptions of someone who they do not know.

Sjöstrand et al (2013b) argue that in specific circumstances, strong paternalism may be justified in order to further a greater amount of autonomy later. However, they note that such a general policy (as opposed to in specific circumstances) would probably be self-defeating. Overall, autonomy and liberty are better served by allowing people to make 'objectively bad' decisions; people develop their agency through making decisions about their values and projects, we would begin to overlook the value of negative liberty in favour

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of a 'specific' value of positive liberty, and that the consequences of a paternalistic policy would tend to fail to maximise autonomy. Thus, in the vast majority of cases, it is morally wrong to override the decisions of sufficiently competent patients in order to enforce a 'greater' level of autonomy, particularly where the standard being imposed is one that is being derived from a fairly exclusionary form of autonomy. The holding of religious beliefs, even those that lead to arguably negative outcomes for the patient, does not itself justify a paternalistic invention.

#### 5.3.3 Religion and coping with illness and disease

If accommodating religious beliefs (Tanyi 2002, Skalla 2006)<sup>74</sup> is beneficial to the patient, then we are justified in making those accommodations under a beneficence principle and from care respect. This section provides some data that illustrate that religious beliefs can be good for the patient.

Spiritual and religious beliefs have a profound effect on well-being and quality of life. Explorations of spirituality and religion in medicine have prompted the concept of the *biopsychosocial-spiritual* model of health care. According to Sulmasy (2002), illness is more than something that disturbs the homeostatic mechanisms within the body, it 'disrupts families and workplaces, shatters pre-existing patterns of coping, and raises questions about one's relationship with the transcendent' (Sulmasy 2002 p.26).

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<sup>&</sup>lt;sup>74</sup> Much work in the area of how religious beliefs impact on patient care looks at spirituality, as opposed to, or alongside religion *per se*. Spirituality is a wider and less prescriptive way of writing about patient's approaches to what is *transcendent* - see chapter two. Although spirituality and religion are not synonymous, both types of belief, if they are integrated into the worldview and perform an identity-giving, morality-giving role, can be treated in the same way. I therefore proceed by taking work focused around spirituality and religion as equally relevant to my concern in this section.

The ways patients employ spirituality are varied, for example meditation and contemplation, praying and attending places of worship (Baldacchino, Draper 2001). Application of these strategies help the patient find meaning and growth, and to adapt through the illness. Koenig's (2012) summary of research suggests that religion and/or spirituality (R/S) helped people to cope in adversity (illness, chronic illness, natural disasters etc) in an overwhelming majority of studies. There was a positive relationship between R/S and emotions of wellbeing, happiness, hope and optimism, and also with a sense of meaning and purpose. Greater self-esteem was reported among those with R/S and R/S was also generally linked to lower anxiety and lower depression, although in some situations, depression and anxiety were linked to higher levels of religiousness amongst those with R/S, perhaps due to notions of shame, guilt and punishment in some religious beliefs.

Religion and spirituality can thus be seen as having both a positive and a negative aspect with regards to health. *Positive* religious coping strategies are such things as spiritual support and benevolent religious appraisals of negative situations, and are associated with greater well-being, such as improved mental health status, reduced rates of mortality, stress-related growth, and spiritual growth. Conversely:

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greater use of negative religious coping strategies (alternatively called religious struggles), such as attributions of situations to a punishing God and dissatisfaction with clergy, is tied to indicators of more psychological distress, such as greater depression and anxiety and poorer resolution of the negative life event' (Pargament, McCarthy et al. 2004 p.1202)

Spirituality has been particularly researched in cancer care (Puchalski, Christina M., Kilpatrick et al. 2003). Patients with cancer face spiritually threatening questions, such as "Why me? Why am I suffering? Why do I have pain? What will happen when I die?" (Skalla

2006 p.746) which are closely linked to fundamental worldview questions discussed in chapter 2 (2.1.5). Patient-reported spiritual wellbeing (sense of meaning, being at peace, having faith) is a high predictor of quality of life even when pain and fatigue are high (Brady, Peterman et al. 1999). Religion significantly benefitted neurosurgical patients, particularly in finding hope, comfort and strength, and religious resources were desired by both over half of all religious and non-religious patients and guardians (Ravishankar, Bernstein 2014 p.1904). Astrow et al (2001) indicated that over half of the patients in their study thought it was appropriate for physicians to ask about the patient's spiritual or religious beliefs, although only 9% reported that any member of staff had asked (2001 p.5754). Patients who reported their spiritual needs were unmet also reported lower ratings of quality and satisfaction with care.

Kaldjian et al (1998) observed that among a US population of HIV patients fear of death was more likely in those who felt guilty about having HIV or who perceived HIV as a punishment (from God or in general). It was less likely in those who read the Bible frequently, attended church regularly, or stated that God was their purpose in life (1998 p.105). In women with HIV greater engagement in spiritual activities linked to decreased emotional distress, lower depression, greater optimism, and overall better psychological adaptation (Pargament, McCarthy et al. 2004 p.1202).

Medical educators and medical students consistently underrated the importance of spiritual orientation (such as the AA's 12 Step programme) in recovery from alcoholism compared to the patients and the general population (2007), although the effectiveness of spiritual

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orientation as an intervention is not clear (Galanter, Dermatis et al. 2007, Miller,
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In the mental health field, coping and cognitive appraisal of difficulties can be positively influenced by religion and spirituality. 'Intrinsic religious orientation' (Allport, Ross 1967) – belief in the religion and attempting to live their life according to it – is most associated with the positive influence (Casey 2011). A deferring style (leaving it to God) and 'extrinsic orientation' (Allport, Ross 1967) -going through the motions, following religious activities for reasons of status, expectation etc- are linked more negatively. Positive coping derived from religion and spirituality is reported in Bi-polar disorder, with large numbers finding religious activities a beneficial healthcare intervention. Depression and suicidal behaviour are also reduced in patients reporting positive religious coping (Casey 2011).

The Royal College of psychiatrists (RCP) published a position statement that states there is an:

extensive evidence base in support of the relevance of spirituality and religion in understanding the aetiology of many mental disorders, the benefits of considering spirituality and religion within an overall clinical assessment of a patient's condition, and also the potential benefits of considering spiritual and religious factors within treatment planning (Royal College of Psychiatrists 2013).

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<sup>&</sup>lt;sup>75</sup> Miller notes that their study participants did not increase their spiritual practice and that sessions were poorly attended - if the intervention did not impact on the individual's personal practice then this would severely limit any effects.

The methodological difficulties of study design, plethora of different measurement tools, the issue of correlation and causation, and how the results should be acted upon clinically are cautionary notes that Berlinger (2004) highlights, although more recent studies have been conducted with higher quality (Koenig 2012). It is also important to note that even though religious beliefs can have positive effects for those who already hold them, attempting to convert or introduce R/S to a patient who does not already have them is not what is called for. Varying worldviews are acceptable, not compulsory, and should not be imposed for paternalistic reasons.

#### 5.3.4 Relating to the patient

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Attending to patients' religious views is also a tangible illustration that the healthcare professional cares about the (whole) patient. Care respect involves valuing the thoughts, feelings and beliefs of the patient, accepting them as they are (religious, spiritual, or non-religious), and such a person-centred task requires listening and responding to each person as an individual (Christie, Camp et al. 2012). Listening to patient stories is part of what healthcare professionals do, allowing the important themes of their stories to be incorporated into treatment plans (Mundle, Smith 2013). Allen notes that patients respond better when they perceive the caregiver has qualities of a;

warm and human approach, instilling hope without giving false hope; attending to patients without being asked; seeing the person behind the patient; and being honest, genuine, involved, listening and concerned that the patient gets better (Allen 2006 p.377).

Trust is also an integral part of delivering good care. The relationship of trust to respecting religious beliefs is encapsulated by a participant in one study who comments that:

[w]hen the nurse . . . tells you . . . I respect your religion . . . immediately, I will have trusted her. . . That's half of the work of being a healthcare giver . . . to get the trust of the patient. When the patient trusts you...he will be compliant with care (Padela, Gunter et al. 2012 p.711).

As well as the advantages that come from people being able to practice their religion during illness, there are harms that result from not providing religiously sensitive services. A patient might refuse to eat the food that is available, risking malnourishment 'lack of access to halal food in healthcare settings may impede healing' (Padela, Gunter et al. 2012 p.712) or a patient might not visit the doctor because of concerns about appropriate gender contact. 'They have to try to...heal themselves or... they try to postpone (going to the doctor)' (Padela, Gunter et al. 2012 p.712). Ali and Burchett (2014) found that maternity services in England were insensitive to Muslim women's needs due to lack of knowledge and the discriminatory attitudes expressed by some health care professionals. Similar issues were reported by Reitmanova and Gustafson (2008) in Newfoundland. This poor, inattentive, care puts women and their foetuses at risk of higher mortality and morbidity.

# 5.4 Concluding remarks

In the previous chapter, I concluded that in care respect, religious and worldview type beliefs ought to be properly recognised as a constituent part of the individual person. Their worldview should be acknowledged and responded to as driving deep commitments for that person, even where we disagree or believe them mistaken. As a critical part of the person, religious beliefs should be taken seriously – to do so both the principles of respect for autonomy and beneficence can be applied.

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Respect for autonomy is sometimes supportive of care respect. For example, freedom from interference in one's life-plans is recognised as an important part of liberty. Beauchamp and Childress (2012) impose minimal constrictions on what constitutes an autonomous choice, relying on an internal rationality rather than one which is deeply substantive. However, more restrictive conceptions (e.g. Savulescu, Momeyer 1997) impose a demand for formal rationality which is beyond the experience and interests of most people in their day to day lives, and as such is exclusionary. Generally, if someone broadly understands and can weigh up the nature of the disease and the nature of the treatments offered this is morally and legally adequate – religious beliefs, even bizarre ones, do not essentially compromise autonomy. I argued against requiring a highly critical analysis of truth claims, supporting instead accepting a patient's voluntary, religiously based decision providing they understand broadly the nature of the medical condition and potential outcomes to them and their chosen lives. This is a *sufficient understanding of the facts* required for a valid consent or refusal, because these are the facts that necessitate the decision itself.

A particular exception seems to occur regarding miracles and whether expecting one is so irrational it compromises autonomy. However, what is at stake is not just whether someone is autonomous, but whether we are justified in overriding that. Under care respect sometimes we may be, but poor statistical understanding and irrationality do not automatically determine forced treatment or limits to other parts of care.

It would also be a requirement that it was the individual deciding from their own particular values, not from external control (such as by devout or authoritarian others). This protects people from being manipulated and used by others in contravention of respect for persons. However, the mere presence of externally originating values -after all, as 'second persons' (Code 1987b) this is how all of us acquire our first values- should not be seen as an automatic

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threat. Importantly, it is impossible to know something of the individual patient without discussing the patient's non-medical beliefs (care respect requires attempting to understand the other); and such a discussion will highlight if the individual concerned is acting under coercion. Intervention in this circumstance might, rarely, be justified in order to further a greater amount of autonomy later, in addition to medical best interests, but to do so does risk further undermining the patient's identity.

Respect for autonomy focuses on the negative obligation of not interfering with the patient's decisions, except in the provision of information. However, much of religious belief relates to such issues as specific diets, requesting certain medications or treatment, clothing, social interaction and custom, rites and opportunities for worship; thus, a great many of the ingredients of someone being 'an end in themselves' are not directly covered by respect for autonomy. Respect for persons calls for care, cherishing, and support in terms of flourishing and this is not the natural strength of a respect for autonomy approach.

Beneficence is an obligation in healthcare and offers strong support for accommodating religious beliefs. It maps closely to care respect (CR requires a genuine concern for the wellbeing of, and compassion for the other, which beneficence does not demand) not only in terms of delivering the 'medical' good (Pellegrino, Thomasma 1988) but in terms of supporting wider aspects of patient care. Examples from research show that patients are frequently benefitted by their religious and spiritual beliefs and experience better care (a more successful beneficence) when their religious beliefs are accommodated. Thus, beneficence suggests providing faith services such as meeting dietary or medicine-ingredient needs, because the provision of these things improves a patient's life.

Studies also indicate that patient wellbeing, relationships with staff and access to healthcare can be positively impacted by religious/spiritual beliefs, and negatively affected if those

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beliefs are not respected and accommodated. Having their religious beliefs taken seriously is a signal to the patient that the professional involved in their care is, in some sense, interested in them as a person, not as a bed occupier, inconvenience or as a disease, thus building trust and better relationships with HCPs.

However, a beneficence account can seem inappropriate when a competent and autonomous patient is refusing care and objectively bringing harm upon themselves. In some cases, religion/spirituality can have a negative impact on wellbeing, depending on the individual's relationship with their beliefs (Casey 2011). The care-respect approach, in valuing the particular ends of the particular patient, challenges the assumption that there can be a singular definition of 'best outcome', because a patient may value death or suffering in a very different way to that which HCPs do. However, religious beliefs can sometimes demonstrably result in harms, a violation of the principle of non-maleficence, and limit free choice when it comes to autonomy. Care respect requires this is attended to as well.

It is not the religion per se that drives our respect - nor is it inherently religion that causes these problems. Instead, we have an obligation to an individual person, thus the impact should be looked at on an individual level.

The requirements of a CR based accommodation can now be expanded from the initial three.

- 1. Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.1.6, 2.1.7, 4.1, 4.6)
- 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 2.1.3, 4.5.2), and

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3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).

The request ought to be accommodated where...

- 4. The patient recognizes that the nature and consequences of the condition apply to them in general terms (section 5.2)
- 5. The beliefs the patient holds are genuinely held by them (section 5.3)
- 6. Accommodating the belief affords a benefit to the person requesting the accommodation *on their own terms* (section 4.9, 5.3).

The next chapter, however, considers that we are sometimes justified in placing limits on our accommodation of religious belief, and we can do so from a care respect-based standpoint.

# 6. Limitations on the accommodation of religious belief

I demonstrated in chapter four that care respect (CR) is an ethical position supporting the accommodation of religious beliefs. It does so on the grounds that we have obligations to the universal nature of persons -their ability to be harmed and their ability to have personal ideas of how their life should go; and to the unique particularity of individual persons -shaping what harms them, and what they see as valuable. In chapter five, I related concepts of respect for autonomy (RfA) and beneficence to CR, as these widely used medical ethics concepts occur frequently in discussions of accommodating religious belief. I illustrated that both conceptions can be used to support accommodation, and in some cases, require it. The purpose of this chapter is to explore limits on the extent and nature of accommodations for persons with religious beliefs. Such limits are justifiable, but also modifiable with reference to CR's emphasis on particular and embodied person.

CR does not require that others be sacrificed in order to CR a particular individual. This theme runs throughout the chapter. In the first example, I discuss how CR both provides reasons to tolerate religious beliefs, and to non-arbitrarily limit such tolerance (when CR is absent from the intolerable behaviour).

In the second, I relate CR to issues around harm and argue that harms which cannot be justified by either consent or by reference to the gained benefit of the harmed person cannot be justified under CR. I also explore the concept of dignity and its usefulness in recognising harms which are not immediately biomedical. Certain attitudes towards or from religious beliefs are harmful, and these should not be generally permitted, either.

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I then look at how legislation around freedom, rights and equality place limits based on the need to CR all – at least minimally- for organisations such as the NHS and the UK as a whole. Finally, I return to limits imposed by the possibility of making an accommodation at all, particularly in cases where there may be strong resource constraints. Under CR it is not practically possible to 'pull out all the stops' for everyone all the time. When religiously motivated requests are for costly and/or futile interventions there are strong grounds that if providing them prevents giving adequate CR to everyone, they should not be accommodated. However, CR also recognises that the particular ratio of benefits to burdens means that some forms of accommodation are required, and others may, on occasion, be permissible.

# 6.1 What limits does CR impose?

#### Dillon recognises that:

The concept of respect does not contain the resources for telling us how to treat persons; its function is rather to keep in the forefront of moral consciousness the attitude of valuing persons for their own sake and so, to remind us of the reasons why we should treat persons as morality obliges us to treat them (Dillon 1992a p.114).

That is, in formulating CR, Dillon was not attempting to offer particular methods of enacting CR, but to keep valuing persons as individuals at the forefront of how we ultimately responded to our obligations. Our moral obligations will occasionally demand a limit to what we can accept or give to persons in healthcare, when they act on the basis of their religious beliefs. In the literature, as demonstrated in chapter three, particular problems

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arise from: patients who demand procedures (particularly futile ones) or treatment that might remove resources from others; people who are not patients but impose their version of the religious good on others; and people who judge the moral worth of others, including their carers, according to religious strictures.

#### 6.1.1 Protection of the vulnerable

Although CR values and embraces 'the individual not despite what she is but as she is ordinary, imperfect, limited, incomplete, and always under construction' (Dillon 1992a p.114), there are still grounds for recognising that some people, sometimes, are actually unable to engage in decision making in healthcare. As I demonstrated in the previous section, although a very broad conception of what capacity looks like is care respecting (and indeed may justify accommodating religious beliefs even in a 'miracle case'), it would not be CR to go along with a patient who is not able to assign a weight to the particular issues around a decision. A person needs to know what the impact of the condition is on them as a person, whether the condition will get worse or better, how it will likely affect their life and body, what treatments might work, and if it will lead to their earlier-than-expected death. So long as the patient believes they have a condition that threatens their life or their life plan and that the proposed treatment normally has a good chance of remedying the problem, they may put the values where they please. A person finding the options for treatment incommensurate with their values (even if we find them odd) is not indicative of an inability to recognise the facts of the condition?<sup>6</sup>.

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<sup>&</sup>lt;sup>76</sup> Thus, to be lacking capacity (as discussed in chapter 5.2.1) means a patient is unable to -in relation to a specific decision at a specific time- understand that they have a condition (in simple terms), that the treatment is predicted to do something to resolve the condition or its symptoms, and/or weigh up the options according to their own values.

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This applies in the case of adults deciding for themselves, but respect for autonomy does not extend to giving permission for an autonomous person A to decide for others, who may be people who lack capacity, on the basis of A's own religious belief. Deciding for others is something that usually concerns deciding for those who lack decision making competence and capacity, such as children, thus I do not discuss it in detail in the chapter that follows.

People are 'free to martyr themselves but not their children' (Bock 2008 p.440). Whereas it is accepted that parents may raise their children in particular faiths, there are social preferences for the protection of minors and an assumption that children should be raised in the best interests of the child (Fitchett 2010 p.107). Both circumcision and FGM, as procedures requested for religious and/or cultural reasons which cause an objective harm for no medical benefit are subjects of moral concern (Abbott, Shahriar 2007, Schramm, Gierthmuehlen et al. 2009, Gomella 2012, Schuklenk 2012, Abu Daia 2000, Dettmeyer, Laux et al. 2011).77

However, situations arise in the treatment of minors who are sufficiently competent to make their own decisions, where the child may agree with a religious perspective and be overruled (*Re E.*, 1 FLR 386 [1993]). Legally, since Gillick (*Gillick*, AC 112 [1986]), competent minors may be considered competent to accept treatment, but paradoxically not to refuse it (O'Brien

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<sup>&</sup>lt;sup>77</sup> The FGM Act (*Female Genital Mutilation Act 2003*) makes illegal performing or procuring 'female circumcision'. However, the Act also prevents adult women requesting such a procedure (Provision 2 and 6) even where it would alleviate severe mental harm (Provision 1.2 and 1.5), if the reasoning is linked to ritual or cultural custom. That genital surgery is considered legitimate if based on a woman's perceived notions of what their genitals should look like (regardless of natural variety, and presumably due to some measure of cultural pressure), and on intersex infants because of gender customs, suggests some ethical inconsistency underlying the legal position, even if it is fundamentally based on protecting the vulnerable. However, non-medically-indicated genital surgery on a non-autonomous individual can have little to no justification.

2012). There are social preferences towards paternalism in the case of children, which are considered *prima facie* more compelling than respect for autonomy; however John Harris considers that the right to refuse is a necessary corollary of a right to consent (Harris, John 2003). Unfortunately, this distinction creates a situation in which achieving the legal age of majority is presented as a deciding factor, with a person able to refuse on their 18<sup>th</sup> birthday, but not the day before, irrespective of their actual competency. Broadly, as O'Brien argues (O'Brien 2012) a competent minor who is able to understand the implications of their position in the same way as a competent adult should not be treated differently than that competent adult just because of their age. If it is the nature of persons that we respect, then a younger person is, *ceteris paribus*, no less a person the day before their majority than after it. Ethically, this could require the law to treat minors in the same way as adults (provided they meet the relevant aspects of decision-making competence such as emotional maturity and capacity) in terms of ruling whether or not they can refuse treatment.<sup>78</sup>

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Other areas in which religious beliefs other than the patient's own might present difficulties are in organ donation or in proxy consent for comatose patients with no advance directives. Whereas it would be part of CR to pay attention to the particular needs of a patient's family and friends, particularly around the end of life, in the majority of cases beliefs other than the patient's own cannot be applied to the patient, particularly if some harm may come to the patient because of it.

<sup>&</sup>lt;sup>78</sup> As this topic is a side point to the main purpose of the thesis, I do not further justify this position. 207

#### 6.1.2 We need not tolerate everything

If CR demands accommodation of religiously based requests on the grounds of respecting particular persons, it seems to allow gratuitous harms to come to some to meet the requests of others. This would, of course, be deeply paradoxical. Dillon comments that:

CR does not, however, require us to be uncritical, to tolerate the intolerable, to admire the despicable or the inane (Dillon 1992a p.123).

That is, Dillon recognises there are limits to our toleration of behaviours (our evaluative respect) – we need not endorse everything with which we disagree. In section 6.2 I discuss the concept of tolerance which permits us to pose a limit based on the underpinning focus of CR – a universal respect for particular others. Importantly, CR will also shape the means by which we enforce those limits.

#### 6.1.3 The limits of harm

In the previous two chapters, I argued that a CR perspective is a form of 'recognition respect' and that, among other things, persons are entities that can suffer harms. It would be contrary to the conception of CR's benevolent concern for others to disregard harmful outcomes. Dillon states:

Further, because CR regards all persons as equally valuable, equally worthy of care and of protection from harm, it cannot countenance sacrificing the well-being of one for the sake of another. CR for one is thus constrained by the demand to CR all (Dillon 1992a p.130).

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Such a position supports adopting a non-harming consideration (6.3 below), but also application to larger scale legislation, such as human rights and equalities legislation (6.4 below)

#### 4470 6.1.4 Practical limits

Finally, Dillon comments that the demands of CR themselves have practical limits:

it just does not seem humanly possible to meet everyone with the attention to detail, the effort to understand, the active promotion of their good, and so on, that care respect requires' (Dillon 1992a p.130).

There are real limits on what can be done due to time and energy and resource constraints, we cannot fully know and provide for every need of every person. I discuss these constraints in section 6.5 below. Although constraints of this type are legitimate, there is still a strong demand to give CR a stronger role:

the inappropriateness of always pulling out all the stops for everyone does not mean that it would be either inappropriate or impossible to approach others generally with more constrained, context-sensitive expressions of care respect (Dillon 1992a p.131).

#### 6.2 Toleration

'The paradigm example of toleration is the deliberate decision to refrain from prohibiting, hindering or otherwise coercively interfering with conduct of which one disapproves, although one has the power to do so' (Horton 2000).

Tolerance and toleration, as words, are widely associated with *enduring and putting up with* something we find (morally) unpleasant or reprehensible rather than reacting to negate it, 209

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e.g. protesting, criminalising, insulting, violently fighting or killing. Accommodating of religious beliefs may require HCPs to permit behaviours and follow decisions which seem to be anathema to them (or other patients). Tolerance is often frequently invoked to justify accommodation of religious beliefs with which one disagrees within these contexts, and in society more widely. Being tolerant of beliefs, such as religious beliefs, which differ from one's own is considered by many to be part of living in a civilized and liberal society.

Fiala (2005) describes the process of tolerance thusly:

- 1) I have a negative judgement about this thing (usually a person or his activities, where activity is broadly conceived to include the actions, attitudes, and habits of persons).
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- 2) I could negate this thing.
- 3) I deliberately refrain from negating this thing (Fiala 2005 p.18).

This means that the tolerant person firstly considers (either by use of reason or emotion) a behaviour, belief or characteristic of another to be bad, equivalent to Forst's 'Objection component' (Forst 2004 p.314-315).

Secondly, the tolerator *could* negate it – they need to have the power to act against it. This behavioural part of the objection could be anything from name calling to a political protest to violent assault or imprisonment. Forst emphasises the importance of power relationships in the ability to act against the intolerable both practically and in the setting of limits (Forst 2004 pp.314,315) – for example, a slave does not 'tolerate' their master, because they have little power to do much about it.

Thirdly, however, the tolerator *deliberately* refrains from reacting negatively for some overriding reason, such as a desire for political stability, fear of social consequences, or a moral principle (Engelen, Nys 2008).

#### 6.2.1 Refraining from action

The three key 'reasons' given for refraining from action (that is, reasons for tolerating) are the politically pragmatic, the personally pragmatic, and the moral. Other reasons might include being dispositionally inclined to give others the benefit of the doubt, pacifism, epistemic modesty and cognitive humility regarding the foundation of one's own beliefs, or a belief that some types of responses to intolerable behaviour do not work to change attitudes (Fiala 2005 p.20, Jones 2015 p.19). My focus is particularly on moral tolerance.

Politically pragmatic reasons for refraining from action revolve around the need for stability and security in societies and groups that are not homogenous. In the modern UK, for example, there are a wide variety of possible ethical and cultural standpoints, which if not mediated in some way would result in the oppression of minorities and potential destabilising violence (and the possible reversal of fortunes of the ruling and the ruled). There is thus a practical need to co-exist with others who have different values of the good (Fiala 2005 p.48).

A *personal* pragmatic tolerance occurs when the social consequences for acting intolerantly are worse than those of putting up with the undesirable persons. So, for example, if someone personally believes that Jews are despicable but will be censured extensively for expressing this, they might still employ a Jewish person, or might refrain from abusing and tormenting their Jewish neighbours for fear of arrest.

211

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*Moral tolerance*, however, is driven by the idea that either a) tolerance is a normative good in its own right (good persons must be tolerant, for tolerance is good), or that b) tolerance is a consequence of other moral commitments, such as a liberal respect for persons (e.g. respecting others demands tolerating others, because not tolerating them is not respecting their nature, as persons, to pursue their own purposes).

These different approaches to tolerance can give rise to *paradoxes* of intolerance.

The tolerant racist problem. We can imagine a racist who despises blacks, thinks of them as inferior and subhuman, and who would like to return to segregation or slave ownership. Nevertheless, they refrain from abusing people from ethnic minorities in their neighbourhood, for fear of consequences. For Engelen and Nys (2008), there are no constraints on the reasons that can be given for refraining from negating the unwanted behaviour, so the racist is nevertheless tolerant. If we think there should be some moral context to toleration, that there is something about toleration that 'ought to be good' we must think of the racist as more of a good person than someone who has no desire to abuse those who are different from them.<sup>79</sup>

However, a moral tolerance produces a second problem, the *moral tolerance paradox*. If tolerance is absolutely normative, then it becomes morally right or even morally required to tolerate what is also morally wrong. That is to say, if it is morally wrong to kill for pleasure, and morally right to tolerate behaviour we find immoral, we must therefore tolerate killing for pleasure because toleration is morally right. This seems to contradict the commitment

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<sup>&</sup>lt;sup>79</sup> Not wanting to do away with morality entirely, Engelen and Nys assert that tolerance remains a morally 'second best' solution. For them the moral attitude is in finding fewer things objectionable (Engelen, Nys 2008 p.51).

of morality to achieving good outcomes, and thus to commit us to viewing tolerance as something other than a moral requirement, not something that can be morally expected.

The third tolerance paradox is that of 'drawing the limits'. If tolerance is not absolute (that is, one must not tolerate everything), this recognises that there is some point at which things exceed the limit and may be acted against. However, drawing the line involves invoking other moral commitments that are themselves potentially arbitrary and intolerant. Drawing a boundary between 'us' and 'them' (the intolerable) can be a manifestation of bigotry and intolerance in itself and is therefore fundamentally intolerant (Forst 2004 pp.313-314).

## 6.2.2 Dispelling the paradoxes

Forst agrees that toleration as a concept is difficult if not impossible to develop as a standalone normative value or virtue -it requires justification from other sources:

in order to have a certain content (and specifiable limits), [tolerance] is in need of further normative resources that are not dependent in that same sense. Tolerance is thus, contrary to a common view, not itself a value but rather an attitude called for by other values or principles (Forst 2004 p.314).

There may, for example, be *sufficiently non-arbitrary* normative constraints on what are tolerable behaviours or on what constitutes tolerant behaviour. For Fiala this limit is at 'harm to others' (Fiala 2005 p.47), and for Forst when the intolerable behaviour is not consummate with treating others with a justice-based equality (or if it is based on arbitrary characteristics, such as skin colour) (Forst 2004 p.322). Thus, whereas a strictly normative tolerance would seem to require toleration of intolerance, one arising from other

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obligations- such as respect for persons- makes it legitimate to reject toleration if respect for persons is violated.

#### 6.2.3 CR and tolerance

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Under CR tolerance is not, in and of itself, a moral good, but it arises as a moral reaction to the understanding that *all* people are *intrinsically* deserving of respect and care, of having their choices, identities and experiences acknowledged and understood. The shared experience of human persons in their capacity to be harmed and to have individual values is a sufficiently non-arbitrary basis on which moral tolerance can be based. Fiala's account of tolerance, requiring people to take seriously the importance of what they are asking others to do, closely resembles the CR approach to particularism (section 4.4). We therefore ought to tolerate things out of a recognition that the people we object to are also people with identities, needs, vulnerabilities and ability to feel pain and suffering as we do.

As CR arises from a value we give to all people, tolerance becomes by necessity limited at the point where the obligation to, at least minimally, CR others is being ignored or violated. Dillon indicates that '... regarding something as utterly worthless or insignificant or disdaining or having contempt for it is incompatible with respecting it' (Dillon 2014). Thus, when someone treats a person with disdain or contempt, for example, they are not respecting them in the way they deserve as a person.

It is also the case that the way in which negation takes place will be shaped by the underlying principle. For example, recognising that the intolerable behaviour comes from a place of central meaning for a person, or that they are in pain and afraid, are features of a CR approach. A suitable CR response would likely be shaped in a similar way to that suggested by Dworkin in the case of paternalism (Dworkin 1971), and the MCA (*Mental Capacity Act*.

2005 Section 1(6)) for patients with diminished capacity; adoption of the least restrictive option to achieve the good end.

#### 4600 6.3 Harm to others

The concept of 'do no harm' has currency in medical ethics, ranging from *primum non nocere* to Beauchamp and Childress' principle of non-maleficence (Beauchamp, Childress 2012). It is widely accepted that HCPs should not harm their patient, an obligation that is sometimes considered to take absolute priority over the limited (as one cannot be beneficent to all people at all times) duty of beneficence (5.3).

That something is harmful is a powerful indicator that we should not do, or permit done, the harmful act involved. However, the occurrence of a harm alone is not sufficient to act (or refrain from acting). Harms may be inflicted for a number of reasons, including the pursuit of a higher good. This is particularly observable in medicine, where limbs may be broken, food withheld, and the body cut into with the aim of alleviating disease. Although informed consent plays an important role in making permissible actions that would in other contexts be deeply immoral, the limitation is not only permission to do the harm, but whether that harm serves a legitimate good sufficient to outweigh the *prima facie* objection to harmful actions (or inactions). Those goods need not be limited only to the biomedical (5.3.1).

#### 6.3.1 The nature of harms

Beauchamp and Childress consider the harm in their principle of non-maleficence to be 'thwarting, defeating or setting back of some party's interests' (Beauchamp, Childress 2012 p.153) but that some harms can be justified. Vaccination illustrates this, as the minor harm

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of being injected and possibly suffering mild side-effects is justified by appeal to freedom from harmful infectious disease.<sup>80</sup> Nevertheless, non-maleficence remains, for Beauchamp and Childress, a *prima facie* principle requiring a justification to violate. Unsurprisingly, they focus on physical harms- 'especially pain, disability, suffering and death' (Beauchamp, Childress 2012 p.154).

Theoretically at least, the greater the harm, the greater the level of benefit produced needs to be to offset it. Physical harms are generally ascribed greater importance than psychological, social or emotional ones, which is not unproblematic – consider the disparity between funding for physical versus mental conditions as an example. Beath is often presented as the most harmful thing that can be inflicted on another person, whereas torture, an incision or bruise, 'gaslighting', are all somewhere else on the scale of harms. It seems at first glance that the circumstances under which it would be beneficent to allow something as harmful as death would be rare and contingent on determining that some things were indeed, worse than death. What various people might find 'worse than death' is variable, and thus subjective (torture might be the most obvious possibility, but active torturing is not within the NHS remit). In the absence of broad and objective agreement on what constitutes 'worse than death', the options remaining are to believe

<sup>&</sup>lt;sup>80</sup> The difficulty is that in the vaccination case, the individual's benefit is also part of a broader societal benefit, in which someone can benefit without undergoing the harm (Dawson, A. 2007). I do not intend to discuss this interesting issue further here as it detracts from the key point.

<sup>&</sup>lt;sup>81</sup> Reasons for this are complex, of course.

<sup>&</sup>lt;sup>82</sup> Gaslighting is a type of psychological manipulation which makes the target question their own memory, perception, and sanity.

<sup>&</sup>lt;sup>83</sup> I would consider the most likely candidates for 'worse than death' to be unremitting and uncontrollable pain and/or unremitting and irreversible inability to have control over one's life plan. I am tempted to add 'an enforced near-total violation of one's values/integrity' – for example, through torture or oppression. Whether these should be considered authoritative, is a different issue.

that nothing can be worse than death, or to allow for the sufficiently autonomous person whose life and death it is to make the decision, giving respect for autonomy the priority. In Millian terms;

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the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant... Over himself, over his body and mind, the individual is sovereign (Mill 1869 pp.14-15).

In CR, the values held by an autonomous person (at least, regarding themselves) are a fundamental part of their particular identity. Forcing a patient to violate their identity by invading their body is to disrespect the particular and embodied person that they are. This in itself is a harm. Thus, respecting where the individual has chosen to draw the line on what they will accept is part of the CR conception of particularity.

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This is not, however, equivalent to HCPs having an obligation to *facilitate* such harms, such as by assisting a suicide or by otherwise accommodating beliefs that are not in some way beneficent to the patient or respecting of the patient's ends. In the previous chapter, I indicated that for many patients, religious beliefs have a positive benefit. When they do not have a positive benefit (as benefit is determined by the patient), the professional does not have obligations from beneficence to support and accommodate those beliefs. However, a strong obligation remains to minimise the resulting harm – it would not be acceptable to refuse other forms of comfort and supportive care to someone who chooses to reject a particular option. This is because beneficence, and CR, continue to demand that what can reasonably be done should be done – the provision of non-judgemental supportive care.

## 4660 6.3.2 Violations of dignity – a particular kind of harm

One of the things that Pagan patients have experienced (although not exclusively Pagan patients) is a dismissive attitude from staff (3.6.5). On occasion, Pagan patients (and those of other religions, and none) have also reported active hostility and mockery. Staff themselves can also experience discrimination from colleagues/managers, patients and the patient's kin (King's Fund 2015). These are not the issues of life or death found in treatment refusals, and they are not dramatic, but they are insidious and every-day, affecting patients and potentially leading to professional misconduct charges (Castledine 2002). They are an important ethical issue.

Dignity is a term often used in discussion of these kind of behaviours, although its

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meaningful use in medical ethics is challenged (Rosen 2012, Beyleveld 2001 and see below). The Social Care Institute considers that dignified care 'means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect, regardless of difference' (Social Care Institute for Excellence 2013). Violations of dignity include name calling, ignoring and disparaging, mishandling personal possessions, ignoring privacy or modesty concerns, and proselytising. Intentional or thoughtless violations of dignity- no matter how common- such as entering rooms without knocking, not making oneself known to the patient, and hospital gowns giving poor coverage of intimate areas are harms. They are not harms on the scale of bodily damage, but addressing them is not only beneficial to religious patients but to others as well (Equality and Human Rights Commission 2014).

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In Bioethics, despite its use in healthcare literature, the concept of 'dignity' has been described as ambiguous (Sulmasy 2013) and vague (Harris, J. 1998). This makes it difficult, or worthless (Macklin 2003) to use as a meaningful term in ethical conflicts. However Sulmasy (2013) considers dignity to be meaningful when used in three overlapping ways: an

intrinsic way- a reference to the inherent worth of human beings; an attributed way, where conventional value is placed on a set of traits or conditions (such as gross poverty or intractable suffering or immodesty); and inflorescently - a reference to flourishing and human excellence (such as being dignified in adversity). These conceptions of dignity seem closely related to concepts within CR for persons. In particular, the sense that intrinsic value arises from something being the kind of thing it is, so we have a recognition respect for (e.g.) humans (Darwall 1977), and that intrinsic value shapes our obligations, as discussed in chapter three. In fact, all uses of dignity as regards people, as Sulmasy (2013 p.944) suggests, logically derive from the conception of the intrinsic worth of a particular kind of thing without us first recognising dignity as a thing people possess, we could not talk meaningfully of its being lost or threatened. Dignity, therefore, is used in ways that draw from qualities in the nature of persons that demand we give them recognition respect; we may recognise that persons have equal value, that some things can threaten the nature of what is it to be a person in a worthwhile sense, and that persons also aspire to some form of excellence in their person. Dignity violations are the kind of thing that negatively affect a patient's selfrespect and self-value, making them feel degraded or worthless.<sup>84</sup> CR considers persons to be purposeful in the pursuit of their own values, characterised by being embodied and capable of suffering. Dignity, therefore, is a word for claiming a recognition for these characteristics and CR is responding to them in a way that is particular to the individual, embodied, person. It is possible to have discussions about recognition for persons without

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<sup>&</sup>lt;sup>84</sup> There are some parts of healthcare that are inevitably going to be undignified for many people - having a smear test springs immediately to my mind- but nakedness in front of strangers and lack of privacy around toileting (particularly if bed bound) are other examples. Some dignity harms are inevitable. Nevertheless, such harms should be minimised, particularly as some groups may experience them more acutely, just as some people feel more or less physical pain.

reference to 'dignity', but it is equally possible to make use of the term, particularly when it is used by those who are not in the privileged forum of philosophy and professional ethics. Dignity is usefully read as a word that calls attention to a number of issues about the ethical treatment of others, particularly those which are not connected to discussions of competence or physical harm.

'To ignore, neglect, or disregard something, or to dismiss it lightly, thoughtlessly, or carelessly is to not respect it' (Dillon 1992a p.108). Thus bullying, disparaging, mocking and dismissing are not care respecting, and can be legitimately expressed in terms of being violations of dignity. These kinds of behaviours can have lasting, damaging effects on wellbeing (Wolke, Lereya 2015, Torjesen 2018). Whereas some harms in medicine may be justified in pursuit of another good, such as side effects in exchange for cure, no principle supports the harms caused by bullying or similar behaviours.

Dillon also remarks that 'I require my own care respect' (Dillon 1992a p.129). Health professionals are also entitled to CR and as such, do not need to accept dignity threatening actions from patients. For some persons with religious (and non-religious) beliefs, there are deep and identity-conferring views that certain groups of people are not entitled to the level of respect they themselves are, for example those who believe homosexuals or transgender folk are morally corrupt, those who view women as inferior and non-authoritative, and those who oppose religions not their own. Whereas CR and the HCPs sense of duty and care towards these patients as persons -who may never have had opportunity to revise their views and are currently vulnerable- urges compassion and limits what might be considered as appropriate negation of a patient's insulting behaviour, it is nevertheless the case that the HCP is justified in caring about herself (and those others in her care).

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## 6.3.3 Acts versus People

Where conscientious objection claims are accommodated, they are accommodated on the grounds that the objection is to a particular treatment or procedure that violates a core belief-such as 'do not take a life' (General Medical Council 2018, Magelssen 2012). Therefore, it is an objection to the nature of a particular act, rather than a judgement against the worth of another human.

Judgements made against people, such as on the basis of skin colour, sexuality or gender, merit less accommodation than judgements about acts (withdrawing/providing life support, imbibing certain medications, receiving blood, etc). If this were similarly applied to patients, rather than to health professionals - patients who object to having a dressing changed by a black nurse would have to find justification for objecting to having *all* dressings changed.

If discrimination against certain people is, in itself, the thing that needs accommodating – such as a female seeing a female doctor/nurse etc, we cannot rely on acts as the distinguishing feature. Such an accommodation is possible from CR, as CR requires acknowledging the particular situation in which someone finds themselves. For example, someone who has been brought up with certain ideas of modesty and intimacy will find it extremely distressing to be examined by those of a different gender. It would be inappropriate to consider that their distress was less worthy or meaningful than someone distressed following an assault. It can be highly appropriate and care-respecting to accommodate requests for particular types of people for a distressed patient, as members of the public are in a vulnerable position when accessing care and may lack the social and educational privilege and awareness expected of health professionals. However, the NHS is not ethically bound to provide a particular gender/sexuality/race of HCP when to do so is

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not possible (e.g. in an emergency), and nor would it be reasonable to expect health professionals to tolerate violence or persistent abuse.

## 6.4 Legal limits

Limits on healthcare are of course also placed by laws around rights and freedoms. Dillon concedes that:

care is not universalizable, we would be hard pressed to regard it as the whole of morality or as by itself a fully adequate basis for morality. Impartiality and universality are also essential for morality; and the question then becomes how to integrate the demands of emotional connection and detached impartiality (1992a p.130).

CR begins the process, but another way in which this is approached is to enshrine ethical concepts in politico-legal frameworks. These give rise to rights which can be claimed by an individual against the state, institution and sometimes other individuals. Human rights, in particular, are built around the shared interests that people have in living their lives the way they want to and the damage that can be done to them by others, especially powerful others (such as states and institutions), both of which are concerns of CR. However, human rights and related legislation also arise from a recognition of the need for political toleration. Whereas ethical demands (such as to give proper care to a person) might sometimes necessitate acting outside the law when a law is itself unethical, such scenarios are exceptional; in general, legal limitations are accepted as overall promoting human goods.

#### 6.4.1 Religious freedom

In the UK, the Human Rights Act (HRA) of 1998 states that:

1. Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance (Human Rights Act 1998. Art.9: Freedom of thought, conscience and religion.)

The right of freedom of thought, conscience and religion includes 'theistic, non-theistic and atheistic beliefs as well as the right not to profess any religion or belief' (Human Rights Act 1998.) It has been applied not only to the well-known, but also to diverse religions and philosophies such as Baha'i, Scientology, atheism, environmentalism and pacifism (Equality and Human Rights Commission 2006, 2014).

Both recognised religious obligations and individual practices connected to beliefs can be protected under Article 9, provided the belief is genuine, sincere, cogent, serious and related to an important aspect of human life or behaviour (Equality and Human Rights Commission 2014 p.40). Of key relevance is the section that reads 'freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance' (Human Rights Act 1998.). Therefore, a patient (or indeed a member of staff) can make public their religious observances. Attempting to curtail the practices of a religion, and preventing someone dressing, speaking, eating or worshipping in a particular way would be an infringement of their human rights.

However, in common with most other rights and freedoms there are limitations imposed. Article 9 is a qualified right which requires a balance to be struck between the needs of the individual, and the competing considerations of other individuals/groups, organisations, the wider community or society as a whole (Equality and Human Rights Commission 2014 p.41).

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2. Freedom to manifest one's religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others (Human Rights Act 1998.)

It is apparent that the right is only granted so far as it does not impact on the rights of others. An appeal to the notion of religious freedom is couched not as a stand-alone absolute, but as part of a complex of socio-political ideals that also include freedom of expression and freedom from unwarranted harm. So, a religion that demanded human sacrifice of (unwilling) victims could not be defended under human rights legislation, no matter how critical it was to that person's life defining worldviews, because it violated the rights of others to life and would also be a contravention of public safety. It becomes more difficult to draw the line where someone's religion, belief or lifestyle is simply considered undesirable by others, rather than it being illegal and harmful (as human sacrifice would be), such as whether groups and individuals can refuse service to people to whom they object.<sup>85</sup> In the

<sup>&</sup>lt;sup>85</sup> For Feinberg (Feinberg 1988), whereas 'offense' may constitute a reason to impose sanctions of some kind (having sex on a bus should not be treated in the same way as physical violence against a person) these would need to be very different to the kind of state sanction imposed on actively harmful behaviour. However, the 'offense principle' itself is complicated by the fact people can be

UK, religious groups can (under certain circumstances) turn away individuals on the basis of, for example, sexual orientation (Citizens Advice 2018) but public authorities such as the NHS cannot.

The second paragraph of Section 9 also includes a reference to the protection of (public) health. Under this element of the legislation, if something constitutes a threat to health, it may be exempted from religious freedom legislation. As an example, religious animal slaughter could be limited by public health concerns about the spread of bovine TB as it was in R (Surayanda) v Welsh Ministers [2007] (Equality and Human Rights Commission 2014). Recognising that the individual is free to take risks with their own health is what permits their own refusal of care, but public health can provide an overriding concern in certain circumstances. For example, public health concerns can limit the actions of those who want to attend worship whilst quarantined with highly infectious disease. Childhood vaccination is not compulsory in the UK, but those who do not vaccinate their children (on the grounds of rights to a family life and to freedom of religion) could be constrained in a similar way if it were.

It is public health and safety concerns that drive guidance about appropriate dress in a clinical setting (for hygiene and safety reasons), such as being bare below the elbows and not wearing jewellery (Department of Health 2009). Safety constraints - no metal in or near an MRI scanner for example- justifiably limit religious expression under the Act. This can pose difficulties for those who are obligated by their beliefs to wear certain items. <sup>86</sup>

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offended by simple knowledge of a thing occurring, and from a standpoint of hate and bigotry incompatible with equal valuation of all people

<sup>&</sup>lt;sup>86</sup> It has also been suggested that religious icons (such as permanently stationed mezuzah in Israeli hospitals) might be a reservoir of bacteria and viruses (Youngster, Berkovitch et al. 2009). Potentially, this could be ameliorated by (sensitive) cleaning. This would have implications for the deployment

## 6.4.2 Equalities legislation

The Equality Act 2010 merged multiple pieces of legislation into a single framework governing issues such as equal pay and forms of discrimination. Under the Act, certain characteristics are 'protected', which means that individuals cannot be discriminated against on the basis of these characteristics. The protected characteristics are age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; and sexual orientation (The Equality Act 2010.)

The details of Provision 10 explain further about the religion or belief characteristic:

- 1. Religion means any religion and a reference to religion includes a reference to a lack of religion.
- 2. Belief means any religious or philosophical belief and a reference to belief includes a reference to a lack of belief.
- 3. In relation to the protected characteristic of religion or belief—
- (a) a reference to a person who has a particular protected characteristic is a reference to a person of a particular religion or belief;
- (b) a reference to persons who share a protected characteristic is a reference to persons who are of the same religion or belief. (The Equality Act 2010.)

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of religious icons in a hospital environment, but for personal items it is not clear how it would apply any more than to other possessions, such as books, phones and photographs.

Under the Act, individuals and organisations (like the NHS) that provide a service to the public must not treat someone worse just because of one or more protected characteristics (direct discrimination) or apply rules that have a greater impact on those with a protected characteristic (indirect discrimination), unless there is objective (and proportionate) justification (EHRC 2014). Harassment and victimisation on the basis of a protected characteristic, or for association with someone with a protected characteristic, are also prohibited. Notably, the EHRC expressly mentions Paganism within its web guidance on the Equality Act's provision regards religion and belief (EHRC 2017).

The Equality Act goes further than the human rights legislation (of not interfering with the religious freedom of others), and imposes a specific positive duty, called a Public Sector Equality Duty (PSED) on public service to eliminate discrimination, to advance equality of opportunity and to foster equality. For the NHS, this also includes a need to reduce inequalities between patients with protected characteristics in access to, and outcomes from, healthcare services (NHS England 2015), as well as in employment and service provision.

In practical terms, the NHS needs to proactively give proper regard to issues of equality when providing services, both in provision of the health service and in employment. Matters such as a dislike of certain people, because of one's own protected characteristics or theirs, are not considered legitimate reasons for discrimination, and as such a health care professional cannot refuse to treat someone with a particular characteristic. However, particularly in cases where someone's health may be disadvantaged due to a protected characteristic (such as having needs regarding the gender of the people treating them), it is acceptable, and indeed expected, for the NHS to make reasonable preparation in staffing to accommodate it.

The Equality Act does not prevent an employer from making an accommodation, unless doing so would breach discrimination law or other legal requirements such as health and safety legislation. Employers should already consider seriously every request made for reasons relating to religion or belief, both for good practice reasons and to avoid the risk of indirect discrimination (Equality and Human Rights Commission 2016 p.6).

The Act and accompanying duty cannot force unreasonable or impossible things to be accommodated, (not does it specify a duty of reasonable accommodation with respect to beliefs) but any justification for non-provision must have an objective component about what would be reasonable. Due to staff levels on a particular night, for example, it might be impossible to guarantee that a female doctor was available in an emergency, but the hospital would be expected to be actively considering the gender mix of staff working in a particular department.

Written in 2009 before the Equality Act came into force, the NHS guidance on Religion and Belief (Department of Health 2009) provided useful case studies. In one case, the need for clinical staff to be 'bare below the elbows' to reduce infection risk was at odds with the modesty requirements of some Muslim staff. It was recognised that the dress code was a legitimate and proportionate response to protecting patients, but some accommodations regarding facilities were made.<sup>87</sup>

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<sup>&</sup>lt;sup>87</sup> Since the publication of the 2009 guidance, some NHS trusts have become more amenable to considering other accommodations for staff regarding clinical wear (such as disposable theatre headscarves and elbow length sleeve coverings), although the British Islamic Medical Association comment that 'employers vary considerably in their implementation of this guidance with some offering considerable flexibility written into their policies whilst others offer very little' (British Islamic Medical Association 2017). It appears there is some reluctance among trusts about some types of religious accommodation for staff members.

The Equality and Human Rights Commission (EHRC) (2014) suggested that a difficulty with the HRA and the Equalities Act is that the thresholds may be set too high when considering if a particular individual has been harmed (in other words, if the reaction of the service provider or employer is disproportionate to the limitations placed on the religious person). There seems to be a reluctance to support human rights claims when the individual is apparently merely motivated to do something by their religion, rather than required to do so under its tenets. From a CR perspective, a tendency to reject individualised interpretations of beliefs would be problematic and an unfair limitation. The concern of medical ethics, as outlined in the previous chapter, should be the interaction with individuals. For example, the wearing of a crucifix pendant or a head covering, see *Begum* and *Eweida* (below), might not be expressly mandated by a religion but is considered a vital element of their practice by the individual.

#### 6.4.3 Case Law

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Human rights and equalities legislation have been tested and clarified in case law.

The general meaning of 'religious belief' (in respect of 'religious worship) was tested in Hodkin and Another (UKSC 77 [2013]). Prior to *Hodkin*, the law had been established in *Segerdal* (2 QB 697 [1970]): a Church of Scientology was not a place of meeting for religious worship and thus a Scientology Church could not be registered to perform weddings. In fact, in Segerdal, Scientology was considered to not be a religion in that it had no reverence for God or a Deity and the participants did not humble themselves before an external entity in worship. Although Buddhism was considered a religion, despite lacking this, Scientology was not. In *Hodkin*, however, the court recognised that (although whether something was a religion or not was fundamentally a theological question) scientology meetings were of a

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sufficiently religious type to have premises registered for a place of marriage. For the purposes of such registration, Lord Toulson saw religion 'as a spiritual or non-secular belief system, held by a group of adherents, which claims to explain mankind's place in the universe and relationship with the infinite, and to teach its adherents how they are to live their lives in conformity with the spiritual understanding associated with the belief system' (UKSC 77 [2013], Lord Toulson). This is similar to the definition in the Charities Act 2011:

"'religion' includes - (i) a religion which involves belief in more than one god, and (ii) a religion which does not involve belief in a god."

Equality and Human rights specific case law includes Begum, Ladele, Eweida and Chaplin. For example in Begum (UKHL 15 [2006]) a schoolgirls entitlement to wear a jilbaab was overridden by the school's uniform policy, and in Ladele (EWCA Civ 1357 [2009]), a woman's Christian beliefs did not entitle her to refuse to register same sex partnerships. She was asked to perform them, but refused, and was sacked. The initial tribunal had determined that her religious freedom did not outweigh the requirements of the 2007 Equality Act (Sexual Orientation) regulations. According to the court of Appeal, who agreed with the tribunal, Ladele's beliefs were not 'a core part' of Christian beliefs, and thus the decision of her employers to terminate her employment was legitimate, as the request to perform civil ceremonies did not prevent her worshipping. In Eweida (EWCA Civ 80 [2010b]), it was ruled that wearing a visible cross was not a requirement of Christianity, 88 and in healthcare directly, in Chaplin v Exeter NHS Trust (ET 1702886/2009 [2010a]), an employment tribunal similarly stated that the requirement to wear a crucifix is not a mandatory requirement of

<sup>&</sup>lt;sup>88</sup> Other staff at British Airways were permitted to wear hijabs, turbans and Kara.

the Christian faith. Addison (2010) finds this ability of courts to determine what 'core beliefs are' is disturbing.

However, not all cases have followed *Begum* and *Eweida*, for example in *Singh* (EWHC 1865 [2008]), it was ruled that a schoolgirl must be allowed to wear a Kara: "the claimant is not obliged by her religion to wear a Kara, it is clearly in her case [an] extremely important indication of her faith."

Equality legislation overall supports the idea of accommodating religious belief, but in common with a right to religious freedom, it is able to restrain the accommodation that is made (and allow exceptions) on particular grounds, such as safety and the interests of others. Striking the correct balance of interests can be difficult. When *Eweida* reached the ECHR in 2013, the decision against her was overturned, as the court determined that too much weight had been given to the employers' evaluation, meaning there had, in fact, been no significant encroachment on the interests of others by Eweida wearing the cross. Chaplin's tribunal ruling, which was heard at the same time, was not overturned, because of the compelling interest in maintaining hygienic practice (Case of Eweida and Others v The United Kingdom, Application numbers:48420/10, 59842/10, 51671/10 and 36516/10 [2013]).

In Pendragon v United Kingdom (1998), a national heritage site used by Druids during the summer solstice was closed by the authorities. When this was challenged by a Druid under Article 9, the ECHR found that the authorities had acted in accordance with the HRA, because they had power to close the site under an Act of Parliament and that their reason for closing the site was anticipation of disorder and damage to the monument itself. The closure was in the interests of public order, and thus justified (Equality and Human Rights

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Commission 2014). For some Pagans, however, this was seen as an 'excuse', and an application of the Act in a discriminatory way.

Most recently, *Lee v Ashers* (UKSC 49 [2018]) it was held that to be discriminatory, the less favourable service or treatment has to prompted by the protected characteristics of the one discriminated against. Objection to a message, in this case 'support gay marriage' on a cake' that was contrary to the religious beliefs of the bakers, did not meet these criteria, as the message would have been refused had anyone requested it.

#### 6.4.4 Ethical consequences

Recognition of a right to those beliefs reflects the critical importance that is given to them as life defining and reconciling beliefs (2.1.6, 2.1.7, 4.5.1). So, in this context, the idea of freedom of religion and belief being a human right is supportive of, and recognises, the idea of the centrality of these types of beliefs. In healthcare ethics terms, therefore, it would seem to be the case that patients and staff are free to practice their religion as they so choose, provided they do not clash with the significant, rights-based interests of others.

CR views 'all persons as equally valuable, equally worthy of care and of protection from harm [but], it cannot countenance sacrificing the well-being of one for the sake of another. CR for one is thus constrained by the demand to CR all' (Dillon 1992a p.130). Thus, legal restrictions aimed at balancing the needs of all persons are a legitimate limit on what must be accommodated or tolerated. However, such limitations need to be regularly reviewed for instances where they are failing to give appropriate respect. In the case of Ladele for example, the tribunal's determination that Ladele's religious freedom did not override equalities legislation, has more resonance with a Care Respect approach than attempting to determine if something is a core part of a belief. The decision in Singh (and the ECHR ruling

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on Eweida) created a more inclusive uniform policy, whereas the effect of Ladele's action was exclusionary. I do note in *Ladele* that she had been swapping ceremonies with others so that the ceremonies were performed without delays or criticism of the partners. This has similarities with conscientious objection clauses in medicine. That said, unlike the medical practitioner's rejection of conducting a terminal procedure (or a baker's refusal to write a particular message), Ladele's objection was to the participants, and not to the act of performing ceremonies.

The right to religious freedom primarily exists to prevent the state (or other public body) from interfering with the religious practices of others. Therefore, it does not directly help when the question is one of supporting others to practice their religion, such as by building chapels in hospitals, providing chaplains or accommodating dietary needs. Religious freedom may permit a patient to refuse care or prevent the health service refusing to serve patients with particular beliefs and obligations, but it could not obligate others to cater to every religious or belief-based need.

# 6.5 The limits of possibility

The idea that 'ought implies can' is a familiar one in ethics, one ascribed to Kant. Although whether the statement is strong or weak regarding motivation to act morally, and other epistemic considerations is debated (Stern 2004); in practical, applied terms, it makes sense to hold the related notion that we cannot have a moral duty to do something which we cannot actually do under the normal limits of reality. This is seen as a flaw of beneficence and care because it seems that we cannot care for all strangers and people we have never met equally well. Even Dillon, who advocates the demanding form of CR, notes 'it just does not seem humanly possible to meet everyone with the attention to detail, the effort to

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understand, the active promotion of their good, and so on, that CR requires' (Dillon 1992a p.130).

Certain elements of healthcare provision make accommodation difficult (or impossible) in some cases. For example, the NHS does not have infinite financial resources and in order to secure good treatment for all patients, some treatments are not made available and some facilities are not universally available (my GP doesn't have an x-ray machine, for example, and hospital patients are most often in shared wards not private rooms) as they would reduce the good that could be done for the majority of patients. Other similar limits are imposed by staff numbers and staff competencies. Whereas more money, facilities and staff are theoretical possibilities, they cannot magically appear in response to the need of a particular scenario, making some demands impossible to meet. Fundamentally, this means that the availability of resources, both in concrete terms (a particular treatment is simply not available) and in allocation terms (whether a proportion of overall resources can be justified for accommodation of religious beliefs) might legitimately limit accommodation. However, the good that accommodation does nevertheless requires accommodation as far as is possible within these limits.

The second element of limitation is that imposed by the limit of medicine. Death is inevitable; it is not possible for some people to recover despite the best efforts of staff, and there reaches a point at which intervention not only has no effect on the condition, it creates harms that do not have the outweighing benefits that ordinarily authorise medical harms (section 6.3). In some cases, continued intervention is requested to allow for a miracle (Orr, Genesen 1997) (discussed in chapter five) and in others there are disputes over Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders (Compassion in Dying 2014) or whether a patient is dead by the religious group's particular criteria (Randhawa,

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Brocklehurst et al. 2012). Accommodating religious beliefs here means both a risk of imposing harms and using resources that would be more effective elsewhere. In most cases, an obligation to provide futile treatments does not exist, but in some limited cases it may be possible for it to be acceptable within constraints.

In the sections that follow, I give three examples of religious belief being accommodated within the limits set by possibility.

## 6.5.1 Chaplaincy

Organisations, such as the National Secular Society (NSS), argue that the NHS should not be using taxpayer money to pay for religious services. Rather, they suggest that such services should be paid for from the chaplain's own religious group. According to their information (National Secular Society 2015), the cost of chaplaincy provision to the NHS was £23 million in 2015, equivalent to 1000 nurses. The provision of religious services seems to be an unnecessary non-lifesaving expense. Moreover, there remains a risk of proselytising and attempts at conversion, which would be inappropriate. In a time when overall, religious adherence is dropping, chaplains may seem doubly redundant.

Those who support the work of chaplains respond that the work they do is essential in supporting patients through the healthcare journey, particularly around the end of life, and that their role is not only relevant to patients of their own belief, but to members of staff and non-denominational patients as well. NHS chaplains, being NHS employees, are bound by the NHS position on non-judgement and not proselytising (Hamburgh 2017, British Broadcasting Corporation 2013a, Preece 2015). It costs money to train and equip someone for a hospital-centric role, a training most effectively provided by the health organisation itself, and many chaplains thus become specialists in hospital and hospice care. The

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religious affiliation is seen as being separate from the health organisation, and perhaps therefore a point of appeal for those unhappy with the system or their care, but also providing a different kind of voice to management when decisions are being made.

The error the NSS makes is in assuming the chaplain's role is a predominantly religious one within an organisation devoted to a secular practice. However, as earlier chapters have covered, the presence of religious and spiritual care has important impacts on patient recovery and wellbeing. Whereas it is true religion affiliation is reducing in the general population, it is still high among the elderly who comprise a significant portion of NHS patients and provides a source of comfort for some non-religious patients in crisis (Preece 2015, Ryan 2015). Likewise, the chaplain can perform the function of establishing the scope of the patient's beliefs and mediating between the patient, their family and healthcare staff -in part establishing the autonomous (or not) nature of the patient's decisions. This task does not seem unessential. It might also be a mistake to consider that the £23 million is a highly significant figure within the NHS operational budget of £116 billion (0.02%)(Ryan 2015). The 1000 nurses the NSS suggest could be paid for with this would be devoted to other tasks, broadly spread over the entire organisation and would be unlikely to fulfil the specialist role played by a chaplain.

NHS chaplains need not be from the predominantly Anglican or Catholic religions, but might also be Muslims, Jews, Free church or humanist (University Hospitals Birmingham 2018). Removing the ability to appoint chaplains directly, and instead being dependent on the finances of a particular community, could fail to meet the spiritual needs of the patient populations. In the case of Paganism, even considering it as a whole rather than as discrete traditions, the number of Pagan patients is small, and there is no 'central church' to be responsible for vetting and training potential chaplains. Small groups (like Pagans) could

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thus find it more difficult to fund chaplains. In the NHS currently, Pagan chaplaincy is provided by volunteers and visitors on an 'as and when' basis or from honorary positions (University Hospitals Birmingham 2018, [Anon] 2009). <sup>89</sup> 90

#### 6.5.2 Requests for substitute treatments

In my case example, Katy in particular rejects animal-derived products. Where specific medications or treatments are rejected because of their contents (or because of the manner of their trialling or development) there are resource implications. In some cases there is no alternative, in others there may be a less effective alternative, and in others, there may be a more expensive one. Whereas many religions and beliefs allow exceptions to their rules on taking in certain substances for health or lifesaving reasons (3.4.2), some individuals still refuse certain types of treatment on these grounds.

There is increasing demand for substitutes that are, for example, differently formulated medications or different operating conditions -such as hyperbaric surgery (Tatham, Patel 2014, Royal College of Surgeons of England 2016). Thus, accommodation here is about making available those alternatives with the additional costs involved, be they direct in terms of expense or indirect in terms of training or recovery time. Making a treatment that is acceptable to people's beliefs has benefits in reducing long-term cost from complications. However, unless that treatment is widespread, it may simply not be economically viable to produce it or use it, and thus it seems on the face of it that the patient should make a choice

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<sup>&</sup>lt;sup>89</sup> The UK Prison service (for whom chaplaincy is a statutory requirement), expressly recruit Pagan chaplains via the auspices of the Pagan Federation (Rudgard 2018).

<sup>&</sup>lt;sup>90</sup> In the US, however, there are several Pagan chaplains recruited specifically to the role (Denora 2017, Ward 2016).

of treatment or no treatment. Neither respect for autonomy nor the NHS guarantee that a *specific* treatment should be available. Some suggest that co-paying the difference might be an option for particularly expensive options; there are already co-payments for dental care, eye tests and wigs (Niemietz 2013, Barrow 2003 p.138). However, and as I shall now turn to discuss, others find co-payments problematic (King's Fund. 2005, Plumridge 2013).

A co-pay option or refusal to provide alternatives may be challenged on several grounds. Firstly, the need for alternative formulations and treatments is not solely an issue for accommodation of belief. People can develop sometimes life-threatening allergies to common ingredients, or be unable to tolerate particular formulations and side effect profiles. There is already a medical driver for alternatives.

Secondly, and related to the first point, to argue that only the biological model of healthcare is appropriate as a reason for alternatives is to deny the wider remit of what it is to care respect someone in their particularity. People have identities, and not just bodies, and it is not possible to respect a person without attending to both of those parts of an embodied whole. This is not the same as funding 'homeopathic hospitals', where the evidence base suggests negligible effects beyond placebo, but instead creating medically effective drugs or procedures that may have benefits outside of the original target group. As an example, Jehovah's Witnesses' refusal of blood products has been a driver for the development of surgical techniques which minimise blood loss, potentially benefitting other patients (Royal College of Surgeons of England 2016).

Finally, the numbers of people for whom the alternative is required is actually relatively small. Rareness does impact on the cost of the treatment and treatments which are not 'value for money' are regularly refused approval by NICE (NHS Choices 2015b). Although copaying seems to be a reasonable request, it inherently disadvantages those of limited means,

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which would mean poor believers were discriminated against, and certainly those who do not have a large congregation or temple to ask for support from. Likewise, it presents a greater burden to those with chronic illnesses who may require a lifetime of special formulation, not a one off or occasional expense. A similar argument applies against requesting the alternatives are fully paid for on a private basis, although there would be no reason to prevent people who could do this from doing so (and perhaps a moral imperative for them to, if they do not sacrifice a certain quality of life to so so), provided the medications were available legally in the UK. Although there may be cases where the treatment simply isn't available at the time and in the place it is needed, if at all, and as such cannot be required, the cost of alternatives is not necessarily a significant limiting factor. It would be important for careful consideration of whether something was cost-effective to be undertaken with the need to provide for a diverse range of patients.

## 6.5.3 Cases of futility

One of the most widely publicised and contentious areas of accommodation are requests for continued treatment in cases of 'medical futility' – a recent example was the case of Charlie Gard, a child with an untreatable medical condition (*re Gard*, 4 WLR 5 [2018b]).<sup>91</sup> Often these cases are particularly emotionally charged because the deaths of loved ones are hard to bear, especially if the loved one is a child.

The term futility is itself contentious (Coonan 2016, Wilkinson, D. J., Savulescu 2011, Doty, Walker 2000). Beauchamp and Childress consider that:

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 $<sup>^{91}</sup>$  In  $re\ Gard$ , the involvement of the media, social media and an international religious group to which the family were not immediately connected added to the complexity of the case.

typically [it] refers to a situation in which irreversibly dying patients have reached the point at which further treatment provides no physiological benefit or is hopeless and becomes optional (Beauchamp, Childress 2012 p.169).

Others support adopting a term such as 'medically inappropriate' (Wilkinson, D. J., Savulescu 2011) in order to clarify the combination of medical experience and value judgement that shapes making such a decision; a term used by Orr and Genesen (1997). Eric Chwang defines futility as uselessness (2009 p.487), but remarks that the true problem is in clarifying why a particular intervention is 'useless', a 'task that clinicians train their entire lives to be able to accomplish' (p. 494). Sokol emphasises the need to state in what way something is futile –in other words 'what exactly does it fail to achieve?'– and adds '[f]urthermore, "futile" suggests that nothing can be done. Recall the ancient medical wisdom: "To cure, sometimes. To relieve, often. To comfort, always." There is always something to be done' (Sokol 2009 BMJ 338 b2222).

For my purposes, a 'medically inappropriate' intervention is one which has no, or a vanishingly small, chance of resolving (or allowing recovery from) the *underlying cause* of the patient's dying (for example, chronic heart failure, metastatic cancer, severe brain injury) when death is imminent or indeed, if brain death has already occurred. In many cases, such an intervention may change nothing about the patient's current state, but in some -particularly cases of intensive cardiopulmonary resuscitation (CPR)- the patient also suffers harms in the process. In most cases, there is no obligation to start or continue such an intervention.

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#### 6.5.3.1 DNACPR and withdrawal of treatment

One example of a medically inappropriate intervention is CPR. Whereas it is an important procedure that has saved many lives, it is also an intervention with a low success rate among patients with irreversible co-morbidities - that is, among patients who are dying from another cause. Medical professionals may therefore seek to place a DNACPR order, indicating that no attempts should be made to resuscitate the patient via CPR, even if there is a slight chance of their life being saved by the intervention. The statistics on successful CPR are bleak- on average only 15-20% of people CPR'd in hospital survive to go home (British Medical Association, the Resuscitation Council (UK), the Royal College of Nursing 2016 p.7)- much less in older/comorbid patients, and 1 or 2 percent among those resuscitated in nursing homes (Doty, Walker 2000 p.12). Even patients who are successfully resuscitated may end up in intensive care, be permanently disabled from brain damage caused by lack of oxygen to the brain during resuscitation, and/or injured by the processbroken ribs are common, as are other broken bones particularly in the elderly (Compassion in Dying 2014). Not only is this harrowing and harmful for the patient, extensive CPR on a patient who is not likely to respond is harrowing and may be harmful to the staff involved (Sokol 2009, Truog 2010). At the same time, the resources used for intensive CPR, both physical and human, could be applied for patients, who could substantially benefit from them (Wilkinson, D. J., Savulescu 2011, Mcdermid, Bagshaw 2009).

On the grounds of religious belief, patients and patients' families might refuse the placing of a DNACPR order, even where the attempt is likely to fail or result in negative outcomes. This is not exclusive to religious beliefs; grieving families and dying patients often overestimate the rate of success of CPR- something some authors link to the unrealistic success rate of CPR on TV shows (Sundar, Do et al. 2015, Doty, Walker 2000). Good practice,

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-unlike the early days of DNR orders, when it commonly occurred without discussion (Mclennan 2011)- is to talk early on with the patient and their family around death and whether CPR is appropriate. However, this does not always occur (Pynn, Morgan et al. 2016), meaning many patients and families suffer unnecessarily. Beyond this, there is no ethical obligation for the professional to perform an intervention that is not in any way indicated. Another intervention that meets the criteria for 'futility' is continuing intensive ventilation or multi-organ support in patients who cannot ever survive without such support. Competent patients may decide for themselves if such support is an acceptable burden or not. However, patients who have permanently lost or will never gain capacity do not have such an option. In these scenarios, withdrawal of treatment is generally considered both ethically and legally justifiable, even if it is painful and difficult for those around the dying patient. Religiously-based requests for such interventions to continue are more common than religiously-based refusals (Orr, Genesen 1997 p.142).

5200 Savulescu (1998b) gives the following hypothetical example:

A three-year-old girl is involved in a car accident and is diagnosed as being brain dead. Her parents refuse to allow her to be taken off the ventilator because according to their religious tradition, a person is dead when the heart and lungs have stopped working, and nothing further can be done. They are also absolutely opposed to organ donation. The intensive care unit is full and another girl is brought in critically injured. With immediate intensive care, there is a good chance she will recover. Her parents are atheists. (They accept that a person is dead when her brain is dead and that organ donation is a good thing) (Savulescu 1998b p.382).

For Savulescu, the beliefs of 'some religious fundamentalist' should not be given treatment 'above the constraints of distributive justice and professional practice standards that apply to the rest of us' (p. 384). His argument is two-fold, that it is unreasonable to prioritise 'false and irrational beliefs' over equally life defining, non-religious views, and that concerns over the availability and efficacy of treatments cannot be disregarded for such beliefs. I rejected the 'irrationality argument' in the previous chapter (section 5.2). However, in futility cases, both the burden to the patient and the need for the resources by other patients for whom intervention would not be futile, are given as reasons why no obligation exists to continue such treatment. Such a view is not immediately discounted by CR - an obligation to CR all requires that sometimes not everything is possible within that constraint.

#### 6.5.3.2 Can we ever continue 'futile' treatments?

However, some authors suggest that, occasionally, there are grounds to accept requests for inappropriate treatment, including Orr and Genesen (1997, 1998) and Truog (2010). For Orr and Genesen, this derives from the importance of religious beliefs, and for Truog, to compassion and understanding of the family left behind. Although 'patient suffering, allocation of scarce resources, and cost must be considered in all treatment decisions' (Orr, Genesen 1998 p386) and '[n]onbeneficial CPR should never be performed when it would cause substantial suffering... or at odds with the interests of the patient ... [or] if there is a credible threat to the health of other patients' (Truog 2010 p.478), sometimes it is justified. Orr and Genesen present this as something being ethically acceptable -rather than obligatory or prohibited (1998 p.387)- because of the 'psychosocial and spiritual' (1998 p.386) elements of medical care. For Truog, actions surrounding the moment of death are highly symbolic and often of great significance to the surviving family. Thus, in a small number of

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cases providing nonbeneficial CPR can be an act of sincere caring and compassion (Truog 2010 p.478).

In the examples of scenarios these authors give, the patients are children, the deaths of which are widely acknowledged as particularly hard to bear. There is no immediate need for the equipment and staff elsewhere (as there is in Savulescu's example above), nor is the intervention going to postpone death for a long length of time (indeed in Truog's example, the child could already have been dead before reaching the ICU). Importantly, the interventions, whereas unable to benefit the patients, also could not harm them in any way of which they were conscious.

What the above authors are suggesting, therefore, is not that religious beliefs or the family's insistence that the HCP 'tries everything' gives an absolute right to futile treatment, but that sometimes caring for the families was sufficiently weighty to justify accommodating them when balanced against the particular harms, care burden and distributive justice issues present in the specific situation. Understanding something of the values held by the patient (and their family) around death, and how it differs from that of the HCPs in these instances would be a requirement of CR, and whereas we may sincerely disagree sometimes, in the absence of other demands, it is permissible to respond to those needs.

### 6.6 Concluding remarks

In the previous chapters, I gave CR as a reason to support accommodating religious beliefs. There is something important and valuable about the deeply held and sincere views which means we facilitate their expression in a healthcare context. I then looked at how a CR based accommodation is supported by RfA and beneficence. In this chapter, I looked at reasons to refuse or limit accommodation of beliefs also in relation to CR. Initially, a limit is imposed

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by the patient's position as an individual and particular person. It encompasses a patient's right to refuse and imposes limits on the ability of others to impose. It hinges on the person having sufficient autonomy to make decisions about their care and recognises that, where someone is not freely deciding and sufficiently understanding, the accommodation of their wishes may be limited in pursuit of best interests.

We are justified in limiting accommodation even if we seek to be tolerant. Commitment to CR forms the basis of tolerance, and it also imposes the limit. We would not need to tolerate, or accommodate, beliefs that are not at least minimally care respecting of others. Additionally, I am particularly struck by Fiala's invocation of *imagination*, an engagement of empathy which, combined with a knowledge of the all-encompassing nature of worldviews, asks for both humility with regards to one's own position and willingness to see things from another point of view (Fiala 2005 p.33). Although tolerance itself may not be the only way to achieve ethical accommodation of healthcare, it seems that preparedness to enter into that kind of reflection is a good basis on which to approach the issue in the first place.

Another limit is imposed by harms. Aside from those harms directly chosen for oneself, a belief that requires others to be harmed in order to fulfil it is a legitimate limitation on accommodation. I recognise that the scale of those harms and the ability of the patient to recognise them as harms might modify responses, but conclude that nevertheless, beliefs that harm others need not be accommodated. In fact, this balancing of harms to others appears in all of the limits, suggesting it has a high justification.

Limits are supported by a framework of rights and equality, which call for accommodation and recognise the legitimate interest of society in protecting itself. Thus, adequate attention must be paid to the values of persons, and accommodating religious beliefs is part of that

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5280 process. However, particularly where individual rights might threaten the equally significant rights of others, limits are legitimately imposed.

The final limit is that imposed by the necessary constraint of possibility and limited resources. There is no obligation to provide what simply does not exist -such as a particular treatment or a cure for the incurable. Nor is there an obligation to provide something that can have no benefit- such as futile treatment. However, below the level of impossible there are opportunities to determine that whereas accommodation is not morally required, it may be morally permissible- such as the use of expensive but futile technology in some circumstances. I also advocate that the provision of services such as chaplaincy or substitute treatments, while necessarily constrained by available resources, perform a critically important function and thus ought to be part of the accommodation of beliefs.

Thus, the CR approach to accommodation can be again expanded to include limitations imposed by the needs of others, giving the following eight requirements.

- 1. Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.1.6, 4.1, 4.6)
- 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 4.5.2), and
- 3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).
- 4. The patient recognizes that the nature and consequences of the condition apply to them in general terms (section 5.2, 5.4)
- 5. The beliefs the patient holds are genuinely held by them (section 5.3, 5.4)

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- 6. Accommodating the belief affords a benefit to the person requesting the accommodation *on their own terms* (section 4.9, 5.3).
- 7. The accommodation does not harm others in a way not in keeping with care respecting them (section 6.3),
- 8. The accommodation is achievable within the restrictions of limited resources (section 6.5).

Several authors have proposed 'weighting systems' for balancing the reasons why accommodation is justified against the reasons why it might be limited in any particular healthcare scenario. In the next two chapters, I critically examine those systems in light of CR and present a modified version of a weighting system that incorporates the requirements of CR.

# 7. Balancing conflicting obligations: weighting system approaches

In chapter four, I established that accommodations for religious belief in healthcare derive from care respect (CR) for particular persons. In chapter five, I showed that respect for autonomy (RfA) and beneficence, two commonly used justifications for accommodation of religious beliefs, both meet and fail to meet the needs of a CR approach to accommodation. In chapter six, I illustrated why there are necessary limits on accommodation, also supported by CR, but that accommodation is possible and required, within and sometimes despite those limits.

In this chapter, I look further at how CR might be balanced in practice. In any given accommodation of beliefs scenario, the precise mix of obligations to accommodate and to limit will be different from other examples. There is therefore a need to balance conflicting principles and obligations in any given scenario. I begin the chapter by giving the core obligations that arise from a CR perspective in relation to the role of religious beliefs in particular persons.

Two authors have created 'weighting systems' (Buryska 2001, Bock 2008) with an intent to clarify which principles or rules ought to predominate – those which would permit the accommodation or those that would not. The systems act as a tool for determining if a particular accommodation is merited in the case at hand. The ideal system is successful if it accurately identifies whether an accommodation requested on the basis of Pagan beliefs has a strong weight according to the CR concept. If a tool discriminates unfairly against Pagan beliefs, accommodates too broadly, or does not capture the important issues, it is not effective.

248

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In this chapter I sequentially critique Buryska's (2001) and Bock's (2008) multi-factored weighting systems against the needs of an effective CR based system. In particular, both systems build on the work of Wreen (1991) and Orr and Genesen (1997, 1998) whose papers have been used earlier in the thesis in support of a CR approach. However, a misunderstanding of Wreen featured in Orr and Genesen's account is magnified in the systems, potentially leading to over-emphasis on shared community values by Buryska and by Bock. This is potentially discriminatory against those in small communities, and it detracts from the CR concern with the role belief plays in the life of a particular individual. Suggestions such as giving more weight based on the assertion of negative rights, the strength of physician autonomy and the traditional basis of some beliefs are also discounted as inappropriate for a CR account. A no-harm to others condition is upheld. A suggestion for the use of 'religious interpreters' could also be incorporated into a CR based accommodation, as an adjunct to balancing rather than as a criterion in its own right. I use the critiques and limitations of the balancing methods used in this chapter as the basis for a new weighting system in the chapter following.

# 7.1 Meeting the demands of CR in the accommodation of religious belief

Care respect is a very broad moral norm that requires further *specifying* (narrowing down in scope for healthcare) and further *balancing* (Paulo 2016, Richardson 2000). The approach of this chapter is to see if weighting systems successfully clarify which of CR's moral oughts take precedence, through the process of balancing. Balancing of moral norms occurs regularly in health care and ethics. For example, Principlism as represented by Beauchamp and Childress (Beauchamp, Childress 2012 pp.17-24), is a set of competing *prima facie* (Ross

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1946) ethical norms (Beauchamp, Childress 2012 pp.15-16). By balancing- that is, by 'finding reasons to support beliefs about which moral norms ought to prevail' (Beauchamp, Childress 2012 pp.20-24), it becomes easier to make judgements based on the underlying moral norms. Whereas it is unlikely that an absolute answer can be produced by weighting systems, 'the more weight on the side of accommodation, the more inclined we should be to accommodate the request' (2008 p.438).

From the work thus far, the following general requirements of CR in healthcare have emerged. CR requires:

- 1. Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.1.6, 4.1, 4.6)
- 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 4.5.2), and
- 3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).

Taking seriously, as a reminder, means 'approaching something with the recognition that it could morally necessitate a change in our focus, attitudes and actions' (section 4.1). Equally, it involves perceiving with a 'loving eye' (section 4.4 and Frye 1983 p.82). As a consequence of this particular approach, we are not only justified in making accommodations for religious belief, in many cases we are obligated to do so. To do otherwise is to fail to properly respect the person with the belief.

In the fifth chapter, I demonstrated that although RfA and beneficence are used as reasons for accommodating religious beliefs in healthcare, they do not necessarily operate according to CR principles and thus sometimes fail to demonstrate CR. However, certain aspects do 250

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support the care respect position on accommodating religious beliefs, in particular those that relate to patients needing awareness of the nature of their illness and consequences of treatment, the voluntariness of the belief, and the benefit which is gained by the patient. Thus, in addition to the requirements above, the following are also necessary:

- 4. The patient recognizes that the nature and consequences of the condition apply to them in general terms (section 5.2 and 5.4)
- 5. The beliefs the patient holds are genuinely held by them (section 5.2.3 and 5.2.4)
  - 6. Accommodating the belief affords a benefit to the person requesting the accommodation *on their own terms* (section 4.9).

However, there are situations in which the nature of CR itself can justify not accommodating the religious belief. In the sixth chapter, I identified several justifications derived from concerns about harm to others and matters of social justice and fair allocation of resources. Thus, a care respect approach to accommodating religious claims in healthcare also requires:

- 7. The accommodation does not harm others in a way not in keeping with care respecting them (section 6.3),
- 5400 8. The accommodation is achievable within the restrictions of limited resources (section 6.5).

An ideal weighting system would be responsive to the concerns of care respect as outlined above, to which the nature of the belief is foundational. Under care respect there is a *prima* facie obligation to accommodate a religious belief because all people have values on which they build their particular lives – life reconciling beliefs of which religious beliefs are one type. However, the CR approach also requires limitations because all people also have an interest in not being harmed and thwarted by others.

Buryska (2001) and Bock (2008) have proposed multi-factored 'weighting systems' as an approach to accommodating religious beliefs. These aim to subject the belief and requested accommodation to some kind of assessment process in order to determine the strength of the claims for and against the accommodation. The role which weighting systems play is to capture and articulate the moral complexities of each case, in a focused and structured way.

## 7.2 The origins of the weighting systems – Wreen and Orr and Genesen

Orr and Genesen (1997), extended earlier work on religiously based refusals arguing that sometimes (and thus not absolutely), requests for 'inappropriate' care – that is, care that was not medically indicated- should be met for the same reasons. They based their work on Wreen's use of 'life-reconciling' beliefs to justify accepting religious refusals of care (Wreen 1991 p.128), and also indicated they were unable to give 'clear guidance on when such a stance is professionally or theologically justifiable' (Orr, Genesen 1997 p.146). The subsequent papers attempted to give clearer guidance, with the weighting systems of Buryska (2001) and Bock (2008) building, explicitly or implicitly, on Orr and Genesen, and therefore also on Wreen.

Wreen, a committed anti-paternalist, noted a reluctance to treat 'whimsical' or 'idiosyncratic' beliefs as having the same justificatory power in refusal as religious beliefs; the RfA represented by allowing a Jehovah's Witness to refuse a life-saving blood transfusion seemed more significant than allowing a (hypothetical) refusal by someone who wanted to bleed to increase the number of red objects in the world (Wreen 1991 p.127). Wreen looked for what he termed the 'extrinsic' factor (p.126), something that was not present in all refusal cases. He found his 'extrinsic' factor to be religious belief. For Wreen, the reason these gave

252

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extra weight to a request was the 'supremely important integrating and reconciling function that [religious beliefs] have in a person's life. In an important sense, they fill out the person, and are integral to his personal identity and sense of himself' (p.128). Wreen's concepts were explored in section 4.5.1, and linked to the concept of worldviews (section 2.1.7), where I established that it is not only religious beliefs that have this life-reconciling function, but many similar secular beliefs as well.

Orr and Genesen directly relate their position to Wreen's 1991 paper, claiming that religious beliefs are special (1997 p.143), being beliefs about the attributes of God, attributes of persons, and personal relationship with God (1997 p.142). These are features of identity defining worldviews, as discussed in chapter two, and as such, held by persons (to whom we automatically owe care respect). However, in doing so, they talk of extrinsic (external) values such as those of a religious community, political ideology or culture (1997 p.145). They claim that 'because a value is shared by the patient's community (is extrinsic by Wreen's definition) it should be given more weight than a patient's idiosyncratic choice' (p. 145).

Here there appears to be a slight misconception of Wreen's intent with 'extrinsic'. Wreen's 'extrinsic' as applied to religious belief, is used to represent something *not present in all refusal cases* (Wreen 1991 p.129), rather than as concordance with beliefs sourced outside the self. For Orr and Genesen, however, it seems the community *is* the extrinsic factor, despite communities of all sorts being present in *all* refusals (and requests), be they families, friend networks, political ideologies or religious groups.

Communities may be helpful arbiters of beliefs, providing useful insight or mediatory effect. For example, although some communities believe in messages from God, most will also accept that the community must apply some discernment to the situation (Orr, Genesen 1997 p.144). The authors do note, there are many communities which might also be involved

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in the patient's life, 'for instance family, social community and medical professional community' (1997 p.144), so it is not necessarily the case that a particular community view should hold sway.

For Orr and Genesen, then, the presence of an extrinsic community adds more weight to the belief. A *shared* belief gives more substance than individual idiosyncrasy, even if such values are incorporated into the individual's persona. This is something later authors also seize upon. However, in doing this they neglect the importance of the *nature* of the belief in the individual. Whereas Orr and Genesen are clear that the community does not possess some manner of determinative veto over what the patient can do, as it is the integration of those values into the patient which matters, 'what makes religious values "special" is not only that they are shared by a community, but more important, that they are incorporated by the individual into his or her persona' (Orr, Genesen 1997 p.145), they nevertheless give a stronger weight to beliefs that are shared with others.

The presence of a (religious) community identifies a set of shared values, but CR's concern is mostly with the particular individual. The importance of community to an individual is relevant to that, but Orr and Genesen's religious communities are only evidence that the belief forms part of a life defining and identity concerning worldview, rather than as necessarily being present in themselves. After all, we may determine someone's beliefs in a number of ways, of which their being shared is only one.

#### 7.2.1 The religious interpreter

Orr and Genesen also introduce the novel idea of a religious interpreter (RI) (Orr, Genesen 1997 p.146), which is taken up later by Bock. In a similar way to a conventional interpreter translating between spoken languages, the RI translates the concerns of the different

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'languages' of the medical and the religious paradigms. The RI may help to articulate the belief in question (sovereignty, omnipotence, etc) in such a way that both parties to the conflict may have a clear understanding of the issue. He or she may be able to convince the physician that a belief should be given serious consideration. If, on the other hand, the requestor's concept of the belief is incorrect or unorthodox, or if the faith community believes that the doctrine or principle in question may be flexible in its application, or that it is superseded by other beliefs (for example the finiteness of life, the importance of ministering to the suffering of the patient), the interpreter may be able to dissuade the patient or family from their request. Thus, the religious interpreter has the benefit of being able to develop a more thorough, deeper understanding of a religious group than the healthcare team have time for.

This is a role clearly akin to the position of chaplain, although it need not be restricted to someone in that form of official role. Given the requirement of care respect for a particular and a thorough understanding of the patient, and the reality of healthcare as a situation in which time is a scarce resource, a religious interpreter could be of considerable value in meeting the obligations of a CR approach to accommodation of beliefs. I will discuss this in more detail in the following section, where Bock makes a religious interpreter an integral part of his assessment criteria.

#### 7.2.2 The suggested weighting systems

Buryska (2001), agreed with Orr and Genesen (1997 p.145) that claims on accommodation made on the basis of religious or cultural beliefs are not absolute. Buryska proposes 'some principles for determining when claims based on religious beliefs or cultural sensibilities "trump" other considerations and when they do not' (2001 p.118). He finds claims defensible

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when they are based on appeals to patient autonomy, negative rights, an established community and personal preparedness to suffer the burdens of the accommodation.

Bock (2008) likewise proposes a weighting system, focussed on the need to exclude undesirable and dangerous beliefs from consideration- that is, to add a normative component to what nature of belief ought to be accommodated. Bock determined that claims were more defensible if they were shared by a community, were deeply held, would pass the test of a religious interpreter, and do not harm others.

#### 7.3 Buryska

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Buryska argues that some claims based on religious beliefs are more defensible than others (that is, more deserving of accommodation), and suggests several key questions should be asked in order to establish the defensibility of those claims (2001 p.119). A claim made on the basis of these considerations, he says, is 'prima facie worthy of, and subject to, public, reasoned and respectful discourse. It does not follow that such a claim is absolute' (2001 p.121).

Buryska takes as a starting point (as I established in chapter three) that religious beliefs, spirituality and such are worthy of consideration independent of the claims of their truth or falsity. Pe cites Orr and Genesen's (1997, 1998) account of why religious communities are important. However, Wreen's (1991) account is not cited, despite being the foundation of Orr and Genesen's work. Although Buryska avoids accounts that validate religion as a weight per se, given the error in interpretation made by Orr and Genesen (that religious beliefs were

256

<sup>92</sup> E.g. Savulescu (1998b) and Savulescu & Momeyer (1997)

important because of an extrinsic community, rather than Wreen's meaning of extrinsic factors not found in non-religious requests) Buryska, from the outset, underplays the role of individual belief and consequently over-plays the importance of community.

Buryska gives an example of a patient (2001 p.118) who is comatose following a brain aneurysm and whose family are waiting for a miracle, refusing to allow the life-support to be withdrawn. They 'take over' the family room, being disruptive by playing loud music and singing, thereby making it unavailable to others. Buryska also notes the family are in receipt of state provided medical insurance, which will soon run out.

The ethical issues in the case are a patient lacking in capacity, a decision by the family not the patient- although he shared their beliefs, a miracle (see chapter five), a question of futility and questions of harms, tolerance, and resource use. In the subsections below, I examine Buryska's criteria with respect to the need for and limits of accommodation proposed by CR (above) which address these issues.

#### 7.3.1 Buryska's first criterion

A claim is defensible when it balances patient autonomy against physician beneficence; less so when the physician's conscience (autonomy) is involved, or when societal beneficence in the form of law dictates otherwise (Buryska 2001 p.121).

Buryska's first criterion relates to conditions of ethical or potentially legal conflict. In ethical terms, he identifies conflicting principles, and in legal terms, he recognises that 'the law purports to articulate the societal consensus of what is best for the patient within the broader context of the society, that is, protecting the rights of both the individual and others' (p. 119). He identifies that a refusal of care is a situation where the patient's autonomy is 257

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generally to be placed above the desire by the physician to act beneficently, although the law may also come into play.

He likens the conflict of doctors who believe it would be morally wrong to continue treating in futile cases to doctors who believe it would be morally wrong to perform abortions. In these cases, the physician has the support of professional or legal bodies in refusing (p.120). On the other hand, if a physician wants to treat and it is not futile, this is only a matter of beneficence, which Buryska does not find as strong a principle in this case as autonomy. Unfortunately, this distinction between competing autonomies seems to value the autonomy of the physician as superior to the autonomy of the 'patient' in that the physician has legal support for his 'conscience', 93 rather than both physician and patient being entitled to CR. It also pre-supposes that beneficence cannot take more forms than just biomedical healing.

Interestingly, Buryska considers the family of the patient as part of what he refers to as 'the patient'. Buryska says '[T]hroughout this paper "the patient" will be used to designate not only the identified patient, but also family members, loved ones and others who speak on the patient's behalf and often in the patient's stead' (2001 p.119). Whereas it is important to recognise that strong familial bonds have an impact on decision making, considering the

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<sup>&</sup>lt;sup>93</sup> For a consideration of conscientious objection which of itself falls somewhat outside the remit of the thesis, see discussion in this thesis section 3.6.6. Broadly, I am supportive of conscientious objection within healthcare, the principles that ultimately underlie accommodation of Pagan patients have applicability also to staff. However, as I comment in that section, the role played by professional duty could be a factor of relevance.

two as an item together fails to protect patients from their families (however well meaning), and in the UK at least the next of kin are not a direct substitute for the patient's wishes. Under the Mental Capacity Act (*Mental Capacity Act.* 2005), care for those without capacity must be conducted in the patient's best interest, and the contributions of next of kin are a guide only, not a substitute. Although it is possible to formally create a legal proxy, the grounds on which this authority is created is not a straightforward appeal to transferred autonomy (Wrigley 2015, 2018) therefore it would be legitimate to down-weight the claims of family compared to the decisions of a patient who is able to make them. In cases where the patient is (permanently) unable to make decisions and there is no indication of the patient's position on the matter, the family can be treated beneficently, but they do not, in CR, act as a direct substitute for the patient's own autonomously expressed wishes.

#### 7.3.2 Buryska's second criterion

A claim based on exercise of negative rights only, is easier to defend than one in which positive rights are invoked, since exercise of positive rights often is found in conflict either with a reciprocal autonomy (cooperation in a decision or action) or with principles of justice. (Buryska 2001 p.121)

Generally speaking, a negative right is an obligation to refrain from intervention in the activities or situation of the rights-holder. A positive right exists if the obligation is to do something which is of assistance to the rights-holder (Campbell 2011 p.32). Gillon (1985 p.1890) describes positive and negative rights in terms of their being justified claims that impose positive (to do or provide) or negative duties (to refrain from doing or providing) respectively. Buryska (2001) identifies that, for example, a patient's negative right to not be forced to undergo unwanted treatment (and the corresponding negative duty of the

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physician not to do so) is generally considered less contentious than asserting a positive right for a particular thing (i.e. the right to non-indicated care). Rights of this type share origins with theories of autonomy, particularly libertarian theories. As we are not justified in interfering with the freedom of others, so the only thing we may know for certain is everyone (at least, everyone with autonomy) has a (negative) right not to have their liberties constrained and a corresponding duty to not restrain other's liberties (Berlin 1969, Mill 1869). Justifications for positive rights, on the other hand, are generally held to be more contextual and less universal, linked to demands on beneficence and disliked by libertarians (Bradley 2010, Lorenzi 2017).

Buryska notes that the 'patient's autonomous wishes are set against the caregivers' view of what is in the patient's best interest: beneficence or non-maleficence' (2001 p.119). As also discussed in chapter four, the right of competent patients to refuse care is legally established, as well as morally. If, as Buryska claims, the patient is requesting something futile or inappropriate, they are making a positive claim, not against beneficence (as the intervention will not improve the patient's outcome) but in opposition to the physician's autonomy. This then becomes a conflict of autonomy which Buryska resolves by recourse to the principle of justice, highlighting that positive claims involve the use of costly resources (p. 120).

Buryska is correct in identifying that resource issues are relevant inclusions under CR, but it is not clear that rights discourse is the way to approach this difficulty. It is not automatic that positive rights have a lower weight than negative rights- RfA imposes some positive

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<sup>&</sup>lt;sup>94</sup> Rights can also be construed as being legal rights (which arise from being given entitlement to something by law) or moral rights, which are claimed from ethical principles. The refusal of care is an example of a right that falls into both categories.

duties (Beauchamp, Childress 2012 p.107) such as providing information. Some positive rights (e.g. the right to be given food in hospital at all) benefit far more people -assuming that maximizing benefit is a concern of justice- than would the right to refuse medical care. Nor is it clear that a legal right should automatically 'trump' a purely moral one. The law may, for example, be failing to address a significant moral concern – as it was until the decriminalisation of abortion or the criminalization of marital rape – although it is understandable that health professionals wish to work within legal frameworks.

Buryska also assumes 'the near-absolute value we place on individual identity and personal autonomy' (2001 p.120). CR, in recognizing the value of identity and personal autonomy, includes obligations to *provide for* that are not separable because they arise from the same place- the nature of persons as embodied feeling beings. Beneficence is not only a justification to provide effective treatment, but also to provide meaningful care (section 4.9). The risk of prioritizing negative rights claims, given their close association with classical senses of respect for autonomy and persons, criticised in chapter four and five, is to unjustifiably devalue rights grounded in caring for and about others. Thus, a CR version of accommodating religious belief does not require a conventional rights focus.

#### 7.3.3 Buryska's third criterion

A spiritual or cultural claim is generally more defensible when the teachings or values that motivate it are grounded in an identifiable and established community, than when they are peculiar to the one who holds them. This places upon all those participating in such discernment the obligation to be accurately informed concerning the teachings, values and practices of the relevant communities (Buryska 2001 p.122).

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Buryska gives weight-giving status to an identifiable and established community. He also identifies that claims made on religious grounds do so by invoking the weight of a particular religious tradition. If this is so, if someone wishes to use their belonging to a community or belief system to be a justification for their claim, the claim must be one that actually is derived from the cited community (2001 p.120).

Buryska then does more work on identifying why communities add weight to a belief. Although he is not concerned with the truth or falsity of religious beliefs *per se*, he wants to test the validity of the individual insight or interpretation, not unlike Savulescu and Momeyer (1997). Buryska suggests, therefore, that communities offer epistemic resources that support the 'truth claims' of individuals'95 (2001 pp.120-121) rather than an individual carrying the burden of justification themselves. Buryska acknowledges that in science there are moments of individual insight which are correct but rejected by the community96 – and thus, the same would happen in religion (2001 p.121). However, he asserts that overall the religious community, like the scientific one, builds on those things that have withstood the test of time and have survived challenge. He considers this a strength, and, indeed it can be, however adopting a policy of rejecting all outliers would devalue the insights of scientists like Galileo or the ethical position of the Buddha for a long time. Buryska goes on to state that:

Without such a foundation in community there is nothing to distinguish a claim motivated by cultural values or religious beliefs from one based

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<sup>&</sup>lt;sup>95</sup> Buryska does not mean to establish the objective veracity of the belief, but that they are true within the context of the religion's worldview.

<sup>&</sup>lt;sup>96</sup> Examples are numerous- such as Priestly and oxygen theory of combustion, and the rejection of Darwin's and Wallace's theories of evolution.

on unilateral imposition of the individual's will upon others. This is heteronomy, not autonomy (Buryska 2001 p.121).

I am not sure this bold statement is true. Clearly, Buryska is concerned that people do not use religious beliefs (as might the disruptive family in his example) to excuse anti-social behaviour -a point Bock (2008) also makes, or to make aggressive demands for something unconnected to the requirements of their faith. Nevertheless, relying on the presence of a community to do so is potentially problematic, and is also unnecessary.

For example, it is clearly possible to work out when something is derived from a religious type belief through dialogue and discussion with the individual, but this takes time and it also takes understanding and skill. If Buryska had cited Wreen (1991), he would perhaps have noted that the difference between idiosyncratic views that need not be accommodated and religious beliefs which do, is not whether there is a community but whether they are of a particular (often, but not necessarily religious) 'life reconciling' type. Even very individualized viewpoints can fulfil this foundational role, and not all religiously motivated behaviours do so. Additionally, any nascent ethical theory for example, however compelling, would potentially count as a 'unilateral imposition of the will' by this definition, discounted as a basis for decision-making until such time as it gained enough currency. The idea that something can only have value after endorsement by others neglects that in care-respect we are concerned about particular individuals. In my example (section 3.8.1) Paul's view does not appear to meet a prevailing community view, so it might be difficult to give weight on this account.

Of course, this criticism does also depend on the definition of *community*. Care respect, for example, recognises that individuals are particular situated others whose ideas and identity exist substantially and inevitably through exposure to ideas and values expressed by others.

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A Pagan who has not spent a lot of physical time with other Pagans, but who assimilates Pagan beliefs from books and personal experience might have difficulty pointing to a community, but nevertheless has not invented everything they believe wholesale. Paul could perhaps point to a book if a book could represent a community. It would be difficult to claim any idea as wholly idiosyncratic. However, if only a significantly sized community of substantively similar beliefs counts in favour of a belief, then it becomes difficult to tell at what point something has sufficient support to qualify as the type of belief we should give ethical weight to.

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Likewise, the absence of a *formal* community does not equal an entirely self-facing account of will, particularly when the will concerned is actually one that limits itself in terms of duty and obligation, rather than a purely personal 'because I (don't) want'. The obligations and moral promises that form part of a religious belief set are a stark contrast to someone who demanded a treatment just because they thought they were entitled to it because of their individual importance or because they 'felt like it'. In section 4.5.2, I argued that one of the bases of our respect for those with religious beliefs arises from the way in which they generate duties, such as to avoid harm to other living beings, honour the family, and from concerns about the place of humans vis the place of god and the like. Thus, one can tell apart a belief based on cultural values or religious beliefs from a unilateral imposition of will by the extent to which that belief represents fulfilling a strong moral obligation to another person/entity/value. As Magelssen (2012) encapsulates, it is also a matter of integrity.

 $<sup>^{97}</sup>$  For example Living with Honour, A Pagan ethics (Restall Orr 2007) which I cite as evidence for the belief in chapter three

In principle, the idea that a community gives weight if the individual can justify (or have justified) their view in light of the community, can be a fair one. For example, the group identification can be a helpful shorthand to professionals, a signal that the patient's beliefs belong to a worldview already predisposed to being of the life-reconciling type. It still, however, requires the HCP to be familiar enough with those beliefs to recognise if they do fit as claimed, and to recognise that groups are not homogenous - there are, for example, JWs who reject watchtower policy (Gillon, Raanan 2000, Muramoto 1998). The community may also be in a position to represent the wishes of incapacitated members of the community, at least so far as the patient is known to agree with the community view. However, Buryska's view neglects what is so key in the accounts of Wreen (and Orr and Genesen) – namely, that it is the type of belief that a religious belief usually is which does the work in demanding us to accommodate it. An account of respecting religious beliefs cannot be complete without a recognition of exactly what it is about such a belief that makes it worthy of weight. A community is evidence for the type of belief that is held, and perhaps of the quality of the idea, but it is not the belief itself. Relying on community support fails to respect the concrete and particular individual and thus is not in keeping with care respect. Buryska's key point is that the general defensibility of a claim may improve if it coheres to the community view cited in support of it – meaning if the patient claims they are motivated by a core community belief it ought to match that belief. This should not be taken as implying such coherence is *necessary* for a belief to be accommodated in all cases.

However, Buryska also does not make a distinction between communities. One of the problems with including no normative constraints on the type of belief held by the community is that extensive communities exist that are racist, anti-Semitic, Islamophobic etc, (such as neo-Nazis) and/or deeply disablist, homophobic or misogynistic. For HCPs to

265

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support accommodation for community views that are not minimally care respecting of others would also be a failure of CR, as I stated in chapter six. Bock, as discussed later, reintroduces this notion and attempts to impose restrictions on the content of acceptable beliefs.

These types of belief might be ameliorated by the concern of the fourth criterion – which is about who carries the burden of consequences, but it seems that it would be more strongly countered by a clear 'no harm' condition or a requirement for equivalent levels of respect.

#### 7.3.4 Buryska's fourth criterion

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A claim is more defensible when the one making the decision is willing to be responsible ("pay") for the consequences; less so when it is proposed that others bear the burden of responsibility (Buryska 2001 p.122).

Buryska's final statement is closely allied to his second, of negative and positive rights. He steps away from rights to use the language of suffering and burdens. He comments that we are generally more amenable to those who will accept the full consequences of their decision rather than leave others to bear the brunt of the monetary cost, physical pain and emotional suffering that it entails (2001 p.121).

Buryska is keen to point out he is not making a judgement on the integrity or sincerity of individuals who do not match the community view, instead he claims that those who decide to counter a prevailing view should be prepared to accept the consequences of it. He claims we 'tend to regard differently a person who makes a decision and accepts its consequences, than we do someone who makes the same decision and demands that others pay for the consequences' (Buryska 2001 p.122).

There are two ways (at least) that this could be interpreted. Firstly, and in a way that is supporting of not deciding for others, it suggests that we are justified in preventing, say, the parents of young children or the relatives of senile adults imposing burdensome treatments on those who cannot decide for themselves. Such a view would be in keeping with CR. It could also mean, for example, that Katy (section 3.8.2) is permitted her refusal of cosmetic repair, as she is prepared to accept the burden of a poor outcome from surgery (although it is likely the challenge to physician autonomy and beneficence represented by her request for poorer care than indicated would cause some consternation to Buryska).

However, there is also a second reading, which reveals an underlying presumption against obligations to further the ends of others, which would not be in keeping with care respect. He claims that '[s]ocial mores and legal manoeuvres to the contrary notwithstanding, our sense of justice is offended by those who would, without permission or consultation, shift to others the burden of paying for **their** preferences' (2001 p.121) (emphasis in original). <sup>98</sup>

There is some truth in the claim that we dislike paying for other's *preferences*, but not only are religious beliefs often more than simple 'preferences' as earlier work in the thesis has demonstrated, but the fact we dislike doing it is not, of itself, an indication we should not be doing it (we dislike paying bills, paying taxes, obeying speed limits and exercising regularly, for example). Buryska could be suggesting that a preparedness to display integrity in shouldering the burdens of one's position could help pick out those beliefs that are not

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<sup>&</sup>lt;sup>98</sup> Buryska is writing from a USA context in which socialised medicine is not the norm, and in which a broadly libertarian approach holds considerable political capital. Although I do not have the space to engage fully with this interpretation, such a background, even within an environment that recognises duties of beneficence, may be at the root of conceiving obligations in terms of negative rights and a reluctance to fund the healthcare of others. Were the family in his example wealthy enough to not be using medicare (state funded healthcare payments), the outcome could potentially be very different, and were they in the UK, discussion of resource allocation would likely have been more prominent.

'preferences' (which would be justified and indeed illustrative of the depth with which one holds them). However, rather than attributing this to integrity, he requires:

recognition of a basic existential reality: that none of us can please others all the time; that there is often a price to be paid for being visibly different, for "going one's own way," for—in current ethics language—behaving autonomously (Buryska 2001 p.121).

In so doing, he compounds the importance given to communities by marking out the 'different' as less entitled to support, rather than recognizing that individual differences, *per se*, are critical to the care respect perspective. It also seems to be rather forgiving of bullying.

#### 7.4 Bock

Bock (2008) continues to develop the idea of the special standing of religious beliefs, but is concerned that some religious beliefs should not be included because they represent something harmful or abhorrent which he terms 'morally disturbing' (Bock 2008 p.437). Like Orr and Genessen (1997 p.145) Bock builds on the conception of 'integrating and reconciling' views and the importance of this type of belief (Wreen 1991 p.128). Like Buryska, Bock attempts to produce a set of criteria on which requests for accommodation can be weighed. However, unlike Buryska, he wants to impose some form of normative constraint on the beliefs that are accommodated. For Bock, only those beliefs that are 'medically valid' should be given weight (2008 p.437).

His criteria are for a belief to

- i) Be deeply held,
- ii) shared with a community,

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- iii) not be harmful to others,
- 5780 iv) Pass the test of a religious interpreter (Bock 2008 pp.437-438).

#### 7.4.1 Bock's argument

Bock introduces the idea of 'morally disturbing' beliefs by mentioning the murder of children by mothers who have given religious reasons for the killing of their children. He uses the examples of Deanna LaJune Laney (DL) and Andrea Yates (AY), women who killed their own children because of claims they received divine instructions to do so (Ayres 2004, Colb 2003, Resnick 2007). Bock states that '[t]hese beliefs might easily play an "integrating and reconciling" function in the lives of their possessors, but certainly we would not rank these requests on a par with ones based on traditional beliefs' (Bock 2008 p.437). Whilst supportive of the idea that religious beliefs should be accommodated, he justifies his desire to limit 'morally disturbing beliefs' with reference to Ruth Macklin's claim that:

it is one thing to require that cultural, religious, and ethnic groups be treated as equals; that conforms to the principle of justice as equality. It is quite another thing to say that any cultural practice whatever of any group is to be tolerated and respected equally. This latter view is a statement of extreme ethical relativism.' (Macklin 1998 p.21).

Bock is therefore arguing that there are universalisable reasons to restrict certain behaviours. As the justified limitations in the previous chapter confirmed, it is true that we do not have to tolerate all practices, and certainly not those that would be a gross violation of CR (section 6.2). Were the murders of children mandated by a religious belief CR would not accommodate such a thing, as it violates the notions of both care and respect. However, 269

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my first concern with Bock's piece is that the incidents he cites are women who were both subsequently determined to be suffering from mental illnesses. DL was eventually determined not guilty by reason of insanity (psychotic delusions), and AY had severe post-partum psychosis. Several authors have already explored the role of the expectations of motherhood in these cases, impoverished mental health care, legal limitations and the role religion might have played in the child murders (Meier 2002, Hyman 2004, Mclellan 2006, Coodley 2002). If religion did have a part to play, it was perhaps in limiting the options available to these women earlier in their lives and shaping the particular manifestations of their illnesses, not as the direct cause of the killings. As such, these cases do not illustrate Bock's point, although they illustrate some of the difficulties in picking apart religious motivation from psychotic behaviour that uses the trappings of religion (illustrated in this thesis section 3.5), and the potential of some religious leaders (and family members) to severely hamper autonomy (section 5.8.3).

That said, medical ethics will already exclude acts that are grossly harmful to others irrespective of religious motivation because of its very old and very basic principle of not doing harm. The fact that some individualistic views lead people to murder overplays the danger of idiosyncratic belief systems in medical care, relying on producing anti-religious sentiment directed at non-mainstream beliefs. Medical ethics is not somewhere we will find child murder being validated on religious grounds, although the disputes about the insanity defence that the cases provoked are legitimate concerns for the discipline.

My second concern arises when Bock claims 'we would not rank these requests on a par with ones based on *traditional* beliefs' (Bock 2008 p.437, my emphasis). The religious group at the heart of the Yates case, for example, focused on one particular leader, Michael Woroniecki, who apparently promoted an extreme, and plausibly abusive, interpretation of

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Christianity (Commercial Appeal of Memphis 2002, Resnick 2007). Bock is implying that traditional Christianity, rather than its offshoots, is superior, presumably because it does not produce harmful outcomes. From this, it seems that Bock would consider, at the least, that *non-traditional* beliefs were *more* likely to be extreme and/or immoral, and possibly that traditional ones automatically are not. However, even mainstream religious beliefs have the potential to lead to abuses of authority and the suppression of wellbeing of – for example, women who seek terminations of pregnancy, or homosexuals, or infants who are circumcised. As I have covered earlier, Pagans are viewed with suspicion by some, and thus a traditionalist and conservative attitude to what is an acceptable religion is likely to mean Pagans immediately fall foul of the requirements. Modern Paganism would find it difficult to be treated with the same respect that Bock grants to 'traditional' ones. Historian Ronald Hutton (2016) expresses concern over the demand for authenticity and tradition as markers of religious belief in general. Hutton states:

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It seems to relegate to second place, if not to discount altogether, what are usually taken to be the two most important aspects of religious authenticity: the relationship between the adherents of a religion and the deities or spirits whom it honours, and the impact that this makes on a society. If those practising a religious tradition have an overwhelming sense of the genuine in the contacts that they make with their divine

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<sup>&</sup>lt;sup>99</sup> Bock's consideration of tradition may have a conservative anti-new-church outlook that sought to blame the actions on the 'oddness' of the women's religious backgrounds. For example, a contemporaneous newspaper article claimed; 'There's only one antidote to bad religion. The grace, love, hope, and community of good religion' (Commercial Appeal of Memphis 2002). I note that a considered approach to evaluating whether some things were specifically harmful would also probably manage to be an antidote to this concern.

beings, then that tradition is a viable one, and those contacts, not claims of initiatory descent or length of practice, are the core of it (Hutton, Tully 2016).

Although Bock states 'the term *religious belief* in this paper will be broadly construed as any belief that fulfils the functions Wreen describes' (2008 p.437, emphasis original), throughout his criteria, he uses the language of traditional beliefs in support of his position. Likewise, although he accepts a concession to Savulescu's (1998b) critique of Orr and Genesen, expanding 'religion' to include worldviews like atheism, he entertains doubts that non-religious worldviews are equal in scope to religious ones (Bock 2008 p.437). However, despite returning to Wreen's position of integrating and life reconciling beliefs as a prime reason for considering religious views, he replicates Orr and Genesen's (1997) contention that the extrinsic factor that gives weight to religiously motivated refusals is represented by the religious belief being shared by a community, seizing on this as a means to determine if a belief is acceptable.

### 7.4.2 Bock's first criterion; deeply held beliefs

Given that under CR, the way a belief is held (as part of a life reconciling worldview (2.1.5) is crucial, recognising the depth of a belief would initially seem to be an important part of any weighting system. After all, a belief that is not held in a life reconciling way would be less integral to the person for whom CR demands attention be paid. Bock seizes on the depth to which religious beliefs can go as part of someone's framework of meaning, but despite mentioning the importance of the 'integrating and reconciling' function which is the foundation of Wreen's respect for religion earlier in his piece, Bock seems to neglect it here. In giving Wreen's list of potential reasons for respecting religious beliefs (autonomy, rights,

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bodily integrity, religious freedom) (Wreen 1991 pp.126-127), Bock overlooks the fact that only religious freedom due to the integrating and reconciling nature of the belief -and *not* the depth of the belief *per se*- was actually upheld by Wreen. Bock challenges that all deeply held beliefs are equal by comparing the idiosyncratic 'trivial' belief and 'traditional religious beliefs':

To say that there is no real difference between trivial and religious beliefs seems clearly false. Religion—with its literature, rituals and saints—has played a central and sacred role in human society since the beginning, a role that is only poorly fulfilled by ordinary activities. Huston Smith says, "The finitude of mundane existence cannot satisfy the human heart completely. Built into the human makeup is a longing for "more" that the world of everyday experience cannot requite" (p.3). So, even if trivial beliefs can be deeply held, there is something about the human experience that such beliefs fail to capture (Bock 2008 p.439).

Smith's evoking of a 'longing for more' (Smith 2006 (2001) p.3) has more universal resonance than Bock's reliance on tradition. Bock fails to encapsulate what the actual distinction between 'trivial' and 'non-trivial' beliefs is, nor does he demonstrate that an idiosyncratic belief, provided it is not 'trivial', deserves less consideration. In eclectic Paganism, beliefs can be deep, religious and idiosyncratic at the same time – posing a problem for any system that seeks to eliminate idiosyncracy, rather than triviality, from the equation.

However, returning to the concept of worldview from chapter two, it becomes easier to determine where the difference lies between trivial (but deeply held) beliefs and religious beliefs. It is a two-fold difference; firstly (and primarily) it is because religious beliefs are integrated into the person and their worldview in a way that even deeply-held trivial beliefs

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are not. Secondly, religious beliefs tend to be of the type that involve obligations to others, which is something that is generally valued. Having repairing old mustangs as important to one's life (which Bock uses as a 'trivial' belief (2008 p.439)), might be a deeply held belief about the value of classic cars, and a strongly motivating personal project, but would be unlikely to shape someone's worldview and the way they believe we should handle our obligations to others. If such a project was someone's focus of existence, we would absolutely allow it to influence our interactions with the person - similarly for concert pianists with damaged hands- as care respect involves valuing people's individual projects, after all. 100 However, it might not carry the same weight as one that more intensely fulfilled the requirement to shape not only our personal projects but our moral obligations.

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Magelssen (2012) likewise adopts 'deeply held' beliefs as essential for allowing conscientious objection. The importance of integrity as a moral good (Magelssen 2012 pp.18-19) also underpins Magelssen's method, and he is particularly clear that a 'serious violation' of one's moral integrity is the kind leading to the claim 'I couldn't live with myself if...' (2012 p.18). In Magelssen's account, to be the kind of belief that merits accommodation, the belief must be both plausible and deeply held. (2012 pp.19-20)- the other elements of his weighting system appertain to the role of professional duties. To illustrate deeply held beliefs, Magelssen considers a hypothetical doctor (p. 19) who refuses to give emergency treatment to people over the age of 70, on the grounds that they have had 'a good innings' – an example first given by Savulescu (2006). Savulescu, writing on the topic of conscientious objection,

<sup>1000 &#</sup>x27;Continuity theory' (Atchley 1989) holds that maintaining a sense of self (as represented by using one's prior skills, behaviours and attitudes as one ages) is considered to be important to maintaining mental, physical and social health. One's personal projects are thus also profoundly relevant to identity and to CR.

considered that this belief, though plausible, is unallowable because it countervails society's view of acceptable treatment. Magelssen agrees this doctor's objection is unacceptable, but claims it is objectionable on the grounds that it is not 'deeply held'. Problematically however, a view such as that held by this doctor can be *extremely* deeply held as well as plausible – perhaps this doctor has arranged for their own suicide upon retirement so as not to be a burden on society. Savulescu's prioritisation of society's view of acceptable treatment is, however, also potentially damaging, as society may hold beliefs regarding medical care that are not necessarily ethical.

Someone can also hold some religious beliefs in quite a light or trivial way, such as giving lip service to ideas about charity and compassion or using them for personally aggrandising schemes. A religious belief of the type we want to give weight to needs to be deeply (rather than lightly) held because it would not be reasonable to stake one's life and health on something that did not *mean* something deeply important. However, as there are deeply held beliefs that do not act as a component of a 'life reconciling' view, that a belief is deeply held is a *necessary*, but not sufficient, criterion on which to give religious beliefs a weight.

#### 7.4.3 Bock's second criterion - community

Bock (2008) considers that beliefs held by many have greater weight than those held by 'a lone Maverick'. This is because the community gives valuable epistemic resources that are lacking in even the most deeply held and well thought out individual beliefs, with the additional benefit of a long tradition. He builds on Buryska's (2001) position about the value of communities, because Bock claims the peer accountability in communities weeds out 'aberrant and antisocial beliefs' (2008 p.438). Bock illustrates this by reference to Hardwig (1991); we depend on communities of trust relationships for the things we cannot know even

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if otherwise independent and self-reliant. He also considers the supportive nature of the community for taking difficult decisions and the resources for coping.

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Bock's use of 'aberrant and antisocial' (2008 p.438) as the kind of beliefs communities remove is problematic. As Buryska (2001) noted, and in parallel to the academic and scientific community, the aberrant belief can be a right one or a morally good one, and yet also be rejected by the community. 'Antisocial' can have a number of interpretations and Bock does not develop further which society he considers the beliefs to be 'antisocial' in. Considered generally, antisocial beliefs would be those that -if enacted- would cause serious harm or nuisance to others and as such would be covered by the no harm condition he later introduces. Otherwise, we are in the territory of discounting those with beliefs (or lifestyles, or neuroatypicalities) that stray from social norms but are not themselves harmful. Bock does suggest that we might be justified in giving groups that discourage scepticism or questioning less consideration, but nevertheless, they still have greater epistemic resources than the maverick who, again, has not stood the test of time or tradition (2008, footnote on p.438) apparently placing the community resource above the actual content of the belief.

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Hardwig (1991), who Bock cited, looks at the extensive communities that develop in academia and the extent to which trust is required and legitimised in those who are in a better position to oneself in terms of knowledge and having good cause to believe what they believe. This can be summarized by the expression 'if A has good reasons to believe that B has good reasons to believe p, then A has good reasons to believe p' (Hardwig 1991 p.697). Thus, just as physicists who are one of a hundred co-authors on a paper from CERN have good reason to trust the co-authors they may never have actually met, when applied to religious communities, religious leaders, scholars and theologians are established as a trustworthy source of religious guidance. However, as Hardwig expresses, and Bock seems

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to overlook, these are relationships of trust which can be and often are betrayed, such as by the fabrication of study results. If an individual feels themselves betrayed (or let down) by the community in which they originated, they can still identify strongly with many of the beliefs to which they subscribed, but be at great pains to separate themselves, through other beliefs or variant justifications, from that particular community. A tightly cohesive religious community may fail to respond to new challenges or experiences and may not have succeeded in removing aberrant or antisocial beliefs, and it may in fact now be propagating such beliefs. Thus, a community might not support a member, even if the member's views are in other ways coherent and concordant.

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CR recognizes that persons are connected, and that inevitably, are shaped by and through interaction with others (section 5.3.5). However, the internal reference points offered in a single community may not always be the best way of achieving this. In modern Paganism, for example, many eclectic Pagans believe that no single community is correct and thus seek out the truth from multiple different sources, placing them in a position not unlike Bock's 'religious maverick'. Indeed, even within communities (including medical ones), there may be accepted differences of opinion about the best course of action in particular circumstances. Potentially, then, there may be a situation where there are two (or more) potential ways of deciding, for example if one section of a community agrees that the patient's belief is in accordance with their tradition, and another does not so agree. Although this may encourage the patient to revisit their belief, as Savulescu and Momeyer suggested (1997), the simplest solution is to return to the position of whether the belief is of the appropriate, life reconciling sort for the patient concerned, rather than asking different

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communities to resolve their differences.

In reference to Bocks's final point on the benefits in terms of coping gained from being part of a religious group; the resources presented by a religious community are a very positive benefit, but sometimes the community can and does limit the decisions that can be made in a medical context. Wreen (1991) commented on this situation and indicated that this may not be the threat we imagine it to be – but it does remain a risk of which health professionals should be aware. A strong emphasis on community by weighting systems might actually *increase* the risks that the individual is substantively not acting according to their own beliefs by giving priority to others who are not the patient. If the patient cites a community's beliefs as the source of their reasons, it may be useful to have a community with which medical professionals can clarify. However, at the point of decision, it is the life reconciling nature of the patient's own belief, not that of the community, which is critical. Thus, CR based accommodation of religious beliefs does not require the presence of a community to be given the weight that both Bock and Buryska give it.

Bock goes on to explain that the size of the community is also relevant, regardless of the threat this poses to reformers within a religion. He claims a belief shared with a larger community is 'prima facie, more virtuous' (2008 p.438) and therefore more relevant to medicine. He admits this might leave out admirable reformers in the interests of recognising a large number of mainstream religious beliefs, but feels this cost is worth it, particularly if the reformer in question scores highly on the other conditions.

I find the expression 'prima facie more virtuous' worrying, as no attempt to explain what he means by 'virtuous' is forthcoming. Charitably, I can assume what he means is 'carries more weight'. However, he could also mean 'more likely to be morally good', which is a little more contentious. If so, he wants to impose normative constraints on the belief beyond those imposed by the no harm condition, such as the belief being shared, traditional, or time

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honoured. Modern Pagans, with recent, non-traditional, highly individualized religious beliefs would not be adequately identified with such a criterion.

Bock considers that the size of a community is also relevant, although this is done in vague terms. He states that 'If the religious belief has few adherents, this should count against the belief; if the belief is a constituent of one of the world's great religions, this counts in its favour' (2008 p.438) Claims about size are problematic, as for example, whether it should be global or local community that matters. Both globally and in the UK, there are far fewer Pagans than, for example, Muslims, but there are proportionally far fewer Muslims in the UK than in Saudi Arabia. Bock seems to want a criterion that excludes small cults, for example those with autonomy damaging, charismatic and manipulative leadership, but excludes all small groups, such as Paganism, in so doing.

Additionally, the 'World's great religions' (Bock 2008 p.438) are not homogenous. It is unclear if 'a branch of Christianity' would be sufficient, or whether the size of the subset community is the most important consideration.

Elsewhere, Bock speaks of 'tradition' frequently without expanding on his definition of tradition explicitly, thereby not establishing how long it takes to become 'traditional'. Instead he focuses on examples which allude to the long histories of the Abrahamic (and particularly Christian) religions, such as 'literature, saints and rituals' (2008 p.439). His lack of clarity on the 'tradition' concept could exclude new religions from his account of community because they have less history; nor does it exclude, in and of itself, harmful traditions. His exclusion on a temporal basis is not explicit but as newer religions are also smaller, they will struggle to find representation in this criterion.

It is possible that considering the relative numbers of a particular faith within the area served by a particular health provider, could have ethical relevance to allocating resources.

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On a basic consequentialist model, a hospital with a high number of Muslim patients could justify its more extensive provision of Muslim chaplaincy and larger prayer space because such provision would potentially benefit more people than in an area with a tiny Muslim population. This would not necessarily, however, reflect a population with greatest need of the type a Rawlsian approach would favour in terms of allocation.

However, because our motivation for care respecting religious belief arises from the nature of the belief that is held, and not from the number of people who hold it, it is not the case that we would be justified to have no provision even for a very small percentage. The extent of the provision could vary in accordance with the likely demands made on it. However, as it is the importance of the belief to the person that is the main factor driving respect for religious beliefs, we could not be care respecting without some minimum way of meeting each patient's religious need. From discussions in chapter five and six, it would be inappropriate for this to merely take the form of permitting refusals—CR demands a positive obligation to care for the whole person which is likely to involve, at the very least, taking the belief seriously, facilitating spiritual support and offering alternative medications as a minimum. There is not space in this thesis for a full account of how distributive justice versus an appeal to principle might be structured under CR, (and this chapter is particularly focused on reaching a judgement in an individual case, rather than on a wider account) but it is an interesting problem for future work.

## 7.4.4 Bock's third criterion; The religious interpreter

Bock suggests the use of a religious interpreter as one of his criteria, which has been drawn from Orr and Genesen (1998) who originally suggested the concept. A religious interpreter [RI] functions best as a method for helping the staff understand the nature of the belief held

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by the individual concerned, rather than as some 'yes/no' determiner of religious validity (Bock 2008 p.439). As such, the RI is assessing that the claim is based in the patient's reading of a community belief but might also usefully be able to determine where the belief fits in the patient's own worldview.

It would be harder to find a religious interpreter for beliefs (or belief sets) that are not held by a community, and as such it is automatically harder for reformers or the followers of rarer (or unique) belief sets to have someone capable of fulfilling the role. This is a double strike against someone who does not have a sizeable (or local) community, simply because of their size. It is unclear from Bock's suggestion, if the interpreter should be of the same religion as the patient, although they would need to be acceptable to the patient if the process was to work (Bock 2008 p.438).

Religious interpreters might, or might not, be drawn from existing chaplaincy positions, who would initially seem to be natural candidates for the role. Clearly, many of the smaller faiths do not have chaplains at all. Many chaplains are able to appreciate the religious standpoints of those who are not part of their denomination and are called on to do so (Ryan 2015) but the ideas contained within the interpreter concept could stretch wider to sufficiently trained non-denominational people, just as there are now humanist chaplains. The religious interpreter needs to be in a position where they can understand the import and basis of the patient's beliefs *and* the medical imperatives guiding healthcare staff, and particularly importantly be able to communicate effectively with both groups. That it might be difficult to create such a position need not be a reason to disregard its moral value.

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#### 7.4.5 Bock's fourth criterion: Do not harm others

In sum, a "no harm" condition is essential if for no other reason than to reinforce the Hippocratic oath; this condition is defeasible, as in some cases of self-harm, but it serves as a safeguard against runaway patient autonomy and a prevention of harm done to others. If it can be shown that minimal harm will occur and that the belief satisfies the other conditions, then the request may be granted (Bock 2008 p.439).

I agree to the inclusion of a no-harm condition. In fact, this condition *alone* is sufficient to condemn mothers killing their children as in Bock's example. It is reasonable that doctors should not be compelled to do things that will harm others besides the patient, or in the case of children<sup>101</sup> or incompetent adults, at the behest of others. Exceptions can be made in the case where the harm is *voluntarily* accepted by the other concerned -such as in a relatively straightforward live organ donation. If someone asserts that the required accommodations are violating of their own beliefs or rights and thus are harms (CR is something to which all are entitled) there are grounds under CR to limit accommodation (see tolerance and harm sections chapter six). However, *dislike* of a practice or type of person fails to constitute harm (in and of itself), falling more precisely into the category of 'offense' which is not as severe as harm (Feinberg 1988 pp.1-2). Examples of the religious behaviours Pagans might demonstrate others might see as 'offense' could be as diverse as visible tattoos or body modifications, sacrifices, Goddess worship, witchcraft, and prayers to entities

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<sup>&</sup>lt;sup>101</sup> Practitioners of Pagan religions are often afraid that the simple act of raising children as Pagan invites attention from social services. It would be great if there were more empirical work on attitudes to Paganism.

commonly thought demonic, (although I concede this is not what Bock was envisioning by 'harm' here).

Religious values of the Wreen type perform a valuable role in the lives of those who hold them (Feinberg 1988 pp.22 and 44) such that very few things would warrant an intervention. Although some may find themselves disgusted or annoyed by someone's religiously motivated requests, this does not automatically constitute a harm to them. However, that is not to say that the extent to which something is offensive (or illegal) would not have an impact – the sacrifice of a live chicken on an open ward, or the enaction of a sexual ritual would likely be so offensive to people's sensibilities that it would be legitimate to forbid it. 102

#### 7.4.6 Bock's fifth and sixth suggested criteria

Bock also mentions a couple of other possible criteria.

(1) that patients understand the medical situation and the consequences relating to their requests and (2) that patients show a willingness to reason about or discuss their beliefs with the care givers of whom they are making the request ... I fear that it would be too limiting, ruling out many religious believers— individuals who are not used to defending their faith and ones who believe that reasons cannot be given for faith (Bock 2008 p.440).

If the patient doesn't understand the consequences then there is a good argument that sufficient grounds already exist for overruling the patient's decision - this commitment to a

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<sup>&</sup>lt;sup>102</sup> It is a generally accepted principle that it is legitimate for some things to be acceptable when done in certain places, but not in others – although there are also equally legitimate reasons to sometimes widen the permissibility or sometimes restrict permissibility – for example, having sex on a bus vs in one's own home (Feinberg 1988), homosexuals holding hands in public, or misogynistic catcalls.

general concept of respect for autonomy is already clear in Wreen's (1991) original account, is supported by CR, and is discussed in chapter five and six. The second suggestion is rationally attractive, although I recognise the limiting factors. There is a tendency to want fully cohesive and fully integrated explanations for beliefs and actions, which are probably beyond most humans. However, the inclusion of such a criterion *alongside* a religious interpreter would allow those who do wish to defend their belief themselves if they are so capable (whilst having a skilled intermediary if they are not) and therefore reduce the need of relying on a large community. The religious interpreter's role is in the assessment of the type of belief being expressed by the patient, not a requirement *per se*.

# 7.5 Concluding remarks

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To simply state that CR should be used in questions of accommodating religious belief is too broad to be action guiding, thus it is necessary to add further details as to how the various obligations that arise from it can be balanced (Beauchamp, Childress 2012 pp.20-24). Previous chapters have shown that CR both supports and limits the accommodation of religious beliefs, requiring a balance to be struck between support based on the importance of religious beliefs to the person, the beneficent nature of those beliefs, harms and the need to extend care respect to all. In this chapter, I explored, as ways of balancing, two particular weighting systems. Buryska's (2001)and Bock's (2008) multi-factored methodologies have strengths and weaknesses if examined on a care respect approach.

In particular, both authors give a special role to traditional belief communities, claiming these communities give a religious request a stronger weight than where those are absent. However, Bock places too much reliance on the sifting abilities of large, traditional communities, claiming that other kinds of community are harmful and large traditional

communities are not. Buryska places too little, by allowing all communities a central role regardless of whether they are harmful. In the CR approach I advocate, the nature of the belief and the role it plays in shaping the identity and moral conceptions of the individual does not depend on numbers or the historical traditionality of the belief. Whereas the presence of a community might be a shorthand for having epistemic resources devoted to the formulation of beliefs- for Pagans finding such a community or even recognising that it exists is difficult. As I pointed out in the second chapter, some Pagans reject the idea of restricting or ruling over the beliefs of others, finding the dogmatic teachings of Western Religions in particular the very antithesis of their religious beliefs. For those who are suspicious of non-traditional religions, such as Bock, Pagans may also find themselves discriminated against just because their beliefs are odd and unusual.

Other elements of the proposed systems, however, do reflect justified limitations on accommodation. For example, Bock's no-harm condition reflects the harm-to-others limitations imposed by CR in the previous chapter. Bock also re-introduces the idea of the religious interpreter suggested by Orr and Genesen (1997), which could be a useful adjunct to balancing the various requirements of CR, although not as a criterion in its own right. Although Buryska's account depends on issues of rights and legal support, thus is subject to criticisms levelled against conventional notions of impartiality (see chapter four), he is correct in identifying that concerns of justice can add weight against a particular incidence of accommodation.

Notably absent are criteria that *expressly* consider the actual benefit to the believer, or one that recognises the frequently 'obligation imposing' nature of this kind of belief. Both of these are profoundly important in CR to persons and their omission limits the applicability of either system to a CR based accommodation of religious beliefs. In the next chapter, I

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propose a modified weighting system which addresses the need for balancing the different obligations imposed by care respect. I return to the Pagan cases to illustrate how they could be approached by this CR based method and suggest ways in which a CR approach to accommodation could be further developed in healthcare.

# 8. A Care Respect approach to accommodating the religious beliefs of modern Pagans

In the preceding chapters, I argued that life reconciling world views, religious or otherwise, merit accommodation on the basis of their importance; that there are autonomy respecting and beneficent reasons to accommodate claims based on belief; and that CR also limits accommodation in cases of harm to others, resource concerns and in cases where the patient is unable to decide for themselves. In the previous chapter (seven) I critiqued two proposed systems (Buryska 2001, Bock 2008) for balancing the competing obligations of CR, and found that emphasising a link to communities disadvantaged smaller newer religions and that the benefit to the patient merits explicit consideration.

In this chapter, I propose a new 'weighting system', which draws upon and subsequently develops through this application, the work done by the authors discussed in the previous chapter and this thesis as a whole. This weighting system is grounded in the CR perspective (Dillon 1992a), providing a series of five criteria for assessing what ethical weight a religiously motivated claim for accommodation should have. It acts as a framework of reasons in support of (or against) a particular accommodation. The advantage of the methodology is its ability to stress key features such as the identity giving, morally obliging nature of religious beliefs and reinforce which ethical principles should apply in the context of accommodating beliefs, and how.

In general, the more of the criteria a particular claim for accommodation meets, the greater the weight it has. Should a request meet all five criteria it ought definitely to be accommodated. Should it meet only one, then it most likely ought not. Fulfilling the criteria

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6190 in any individual case ought not be made prohibitively demanding for ordinary people, or a potential accommodation discounted simply because of convention and habit within healthcare.

I use the Pagan cases given in chapter three (section 3.8) to illustrate the issues that may arise in, and the principles of, the weighting process, although my proposed methodology should be applicable to other religious type beliefs. In order to support the practical implementation of these criteria, I also highlight three potential areas for development: training, spiritual history taking, and the role of religious interpreters.

# 8.1 Towards a weighting system that works for Pagan patients

Ultimately, (bio)medical ethics is an *applied* discipline. It informs policy making at an institutional national or even global level, and also judgements made in individual cases. Thus, it needs to be responsive to the practical demands of doing the good and right thing in concrete situations. Therefore, although CR offers a broad approach to ethics by linking care and respect for persons in their particularity, it does not, in and of itself, provide clear guidance; further specification and balancing is required. Once I had established the parameters of CR in relation to the importance of religious belief (chapter four), I looked at how that more practically related to areas of ethical concern in healthcare- those ethicolegal principles that were in support of accommodation, and those which might legitimately impose limits.

I begin from the basic position that what is important about religious belief is the role it plays in the life of the individual, one that is fundamental, constituent of their identity and understanding, and one that creates important, obligations, whether that is to a divinity,

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other people, other-than-human-kin or a cause. As CR demands respect for persons in their particularity, and religious beliefs are part of the person's particular identity, religious beliefs begin as *prima facie* deserving of accommodation (chapter two and four). However, CR also has a concern with harms (chapter six) – given that particular persons are embodied and capable of experiencing pain and suffering, and a concern with equality in that all are entitled to CR. Thus, there is also a *prima facie* obligation to prevent harms and inequalities.<sup>103</sup> Under CR we must take people seriously (Buss 1999 p.519 & footnote 4) – that is, openly and genuinely see them as potentially making a moral claim and imposing obligations, and being prepared to modify our actions accordingly.

In so doing, I clarified that a CR approach to accommodating beliefs requires:

- Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.16/2.1.7, 4.1, 4.6)
- 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 4.5.2), and
- 3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).
- 4. The patient recognizes that the nature and consequences of the condition apply to them in general terms (section 5.2, 5.4)
  - 5. The beliefs the patient holds are genuinely held by them (section 5.3, 5.4)

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<sup>&</sup>lt;sup>103</sup> The extent to which Justice related concerns are part of, or adjacent to CR is not fully resolved in the literature, and I have chosen not to argue substantially for one case or another, rather I acknowledge that justice concerns are relevant in medicine, and that CR is able to respond, at least minimally, to that concern.

- 6. Accommodating the belief affords a benefit to the person requesting the accommodation *on their own terms* (section 4.9).
- 7. The accommodation does not harm others in a way not in keeping with care respecting them (section 6.3),
- 8. The accommodation is achievable within the restrictions of limited resources (section 6.5).

In chapter seven, I noted that one approach to applying general and clarified principles like those above was to use a method of weighting. Such a method gives weight to the claim for accommodation if certain criteria are met and reduces the weight if they are not. Although the criteria of Buryska and Bock were unable to clearly offer CR acceptable outcomes in the Pagan examples, the approach itself, with modification, could nevertheless become a useful guide. Hence, the aim of this chapter is to justify a weighting methodology that works for accommodations based on Pagan beliefs and most likely, other beliefs as well.

The care respect weighting method consists of five criteria:

- 1a) The belief is of the reconciling type and
- 1b) is actually held deeply by the patient and
- ic) creates a moral obligation for the patient
- 2) There is a recognisable benefit to the patient that is not restricted to the biomedical sphere
- 3) The request for accommodation is self-regarding and does not require others to be harmed

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4)The patient accepts the consequences of their action and the medical situation giving rise to it

5) It is possible to accommodate the belief.

It may be particularly important for a psychiatric team called in to assess a patient with odd beliefs to work with criteria one and four. A manager might be more focused on whether the accommodation is possible (criteria five) with the resources available. However, they are intended for consideration as an overall whole, so health professionals would need to be prepared to explore all the criteria.

## 8.1.1 The Pagan patients

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Within chapter three, I illustrated several scenarios (section 3.8) that suggest how Pagan beliefs might impact on healthcare. These are based on cases arising from other religions, personal experience, informal reports and knowledge of Pagan beliefs. As I go through my suggested weighting system for religious beliefs, I use these cases to illustrate points.

In case one, (section 3.8.1) a Druid was struggling with the requirements of dialysis, initially refused treatment, and then asked for the presence of a Druid priest during a transplant in order for it to be acceptable. This illustrates the difficulties around compromising standard procedures to a patient's benefit, and touches on issues of resource use, autonomy and refusal of treatment.

In case two, (3.8.2) the Wiccan was rejecting certain products and procedures because they felt they were enduring a legitimate punishment, as well as rejecting some treatments derived from animal sources. Alongside the issue of assessing the capacity and/or rationality

of someone with unusual beliefs, and the problem of medication ingredients, the case raises questions about staff understanding of the patient potentially limiting good care.

In the third case, (3.8.3) there was a decision to be made as to whether a Pagan or a non-Pagan, both of whom had legitimate claims on accommodation, should get the benefit of an earlier scheduled surgery. This case identifies important issues about the nature of belief and whether it is grounds for prioritising one patient's requests over another. It also illustrates the problem of negative attitudes held by staff towards unusual beliefs.

Going through the points made in the previous chapters in conjunction with these examples should illustrate that the five criteria I outline in this chapter successfully accommodate Pagan beliefs where other similar criteria may not, and also draw justifiable limits. Throughout, applying a care-respect approach looks for a particular, compassionate and respectful way of handling the issues that arise.

## 8.2 A new 'weighting system'

#### 8.2.1 The nature of the belief

The nature of the belief is the first of the criteria, and it is split into three components. Each component looks at an element of religious belief which relates to work done in chapters two through five. If someone is making a claim that is based on such a belief, there should be methods available that enable the health care professionals involved to understand that the request is, in fact, based on such a belief. Clues to whether the belief is of this type can be found in several ways. This will include talking with the patient, their relatives, friends, and religious advisers. It will also involve having a good understanding of the basic aspects of many religious beliefs- such as the way in which they intersect with the concept of

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worldview. I discuss and advocate how taking a spiritual history and the use of religious interpreters (RI) can assist in this in a later section. It is important to note that even if a belief seems strange or unusual, this is not enough on its own to counterweight it, given it is of the life reconciling (worldview and identity giving) type.

#### 8.2.1.1 Criterion 1a - The belief is of the reconciling type

In chapter four, I explored what it meant to show 'respect for persons' and 'respect for religious beliefs'. The relationships and values that people have are part of defining who they are as a particular individual. The care respect approach (section 4.4) treats persons as people connected to others and places a low premium on meeting an atomistic standard of rationality and personhood (4.3). We cannot speak of respecting the person without considering what it is that makes them the *particular* person that they are (4.5). So, not only do people deserve recognition respect (Darwall 1977 and thesis section 4.1.1) for being humans who feel and have ideas of how their life should go, but also for being individuals in their unique circumstance (4.4).

Religious beliefs are of a type identified by Wreen as life-defining and reconciling (Wreen 1991 p.128), fulfilling an important role in answering the questions of identity and purpose that are represented by the concept of a Worldview (Sire 2004, Benjamin 1990). This Worldview is not only shaped and informed by religious beliefs, but by any set of beliefs that answer the fundamental questions. Thus, feminism, environmentalism, vegetarianism and political theories (for example) all occupy the same identity giving position. Violating this kind of belief threatens the integrity (Magelssen 2012) of those involved.

As explored in section 2.1, the worldview is a kind of jigsaw (DeWitt 2010) that fits together, each part supporting and informing the others around it, often held unconsciously. As such, it is difficult to challenge specific ideas without it being threatening to the whole individual.

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That is not to say that such challenges are not sometimes appropriate – we do, after all, have the capacity to change our minds about things by reflection, examination or experience- but an entreaty from one worldview, however sincere and urgent, will struggle to find a foothold in another because the underlying frameworks are so different (Benjamin 1990, Luker 1984, DeWitt 2010). Pagan religious worldviews could fall into this category. Accepting the impact of a patient's worldview is built on the concept of care respect – a recognition respect of the value of all human lives built on a shared need to be free of suffering and to express their identity (sections 4.2 and 4.4).

Recognising that a belief has the powerful identity determining characteristics that affect

the care it is appropriate to give is an important step in accommodating that belief. Because of the jigsaw-like structure of worldviews, a newly acquired or insincerely held belief is less likely to support and reflect the other elements of the worldview– that is, it is less likely to be part of the core nature of the person that modifies our treatment of that person. There will always be uncertainties as to where it fits with some other beliefs (our principles can and do conflict), and occasions on which our behaviours do not match our beliefs – we are, after all, still works in progress - but the accommodation a patient requests needs to be related to the belief that is given as the reason to request that particular accommodation. As a consequence, this entails adopting an approach to decision making capacity in which the accommodation a patient seeks needs only reflect what makes sense in the context of

Ethicists are familiar with rigorous examination of aspects of their worldview, but such a reflectiveness is not among the values of many people, and Medical Ethics needs to deal with people as they are. Care respect requires attention to 'where' people are, that is, to their

their worldviews combined with accepting the truth of the condition they are experiencing

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current abilities and understanding. It does not, for example, expect advanced critical skills from people who have never had need of or exposure to them (5.2.1). Underpinning this, are notions that whereas a high level of moral agency may be *sufficient* for moral status, it is not *necessary* (Warren 1997 p.120), that we often esteem particular forms of rationality too highly (Little 1996) or implausibly (McClean 2009), and that we ought to cherish the person that *is* in their concrete particularity (Dillon 1992a p.117). Even those with reduced capacity can hold religious beliefs that should be respected.

It may be the case that a community exists to support and demonstrate the belief is coherent in this way, since beliefs are often integrated into entire system which benefits from the epistemic resources and refining capabilities of the faith group over time (Bock 2008). Criteria such as those of Buryska and Bock however, place such a strong emphasis on the presence of 'traditional community' that the absence of such an immediately obvious community may lead people to conclude the belief is not, or cannot be, of this type. The presence of a large community may be of use when dealing with individuals who have not developed reflectiveness on their own tradition, but the absence of such a community is not of itself sufficient to down-weight the claim, because the true importance comes from the individual's identity defining beliefs.

#### 8.2.1.2 *Criterion 1b - The belief is held by the patient*

In chapter five, I discussed issues around whether religious beliefs posed a threat to patient autonomy. Persons have ideas and preferences for how they want *their* life to go, but also ideas about how other people's lives should go. To serve individual autonomy, it is necessary that the religious belief shaping medical care is the patient's own, not one that has been foisted upon them by others. This is already familiar in medicine as part of the voluntariness component of informed consent (Beauchamp, Childress 2012). Clearly, life reconciling

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beliefs from religious and non-religious worldviews are always shaped by external influences, so it would not be reasonable to exclude beliefs shared by a community of which the patient is (or was) a member simply on that basis. It is true that some sects *are* coercive of members and can actively inhibit them from questioning the community position. Nevertheless, not all constitute autonomy compromising influence (Beauchamp, Childress 2012 p.104).

We cannot know for sure what someone else is thinking, so it is not an easy process to establish whether the individual is under coercion or is simply afraid or torn between alternate courses of action – a problem not unique to matters of religious belief. That identifying a lack of voluntariness is difficult does not mean it is impossible to do. HCPs are already capable of identifying the signs in scenarios where religion is not involved.

#### 8.2.1.3 Criterion 1c - The belief imposes a moral obligation

In my consideration of the importance of religious beliefs in chapter three, I noted there are also good reasons for preferring certain religiously motivated requests over others beyond them being integrated into the patient's worldview. There are types of activities that we generally recognise as being more important than others; those that relate to obligations and duties (4.5.2) rather than those based on personal desires. An example might be allowing someone short notice leave to attend their partner's labour or care for a sick child, rather than for a football match or just because they felt like it.<sup>104</sup> A paradigm example of this kind of moral imperative is a patient who values their relationship with their God more greatly than their physical life if the latter is bought at the cost of breaking a promise to that

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<sup>&</sup>lt;sup>104</sup> That is not to say that letting people take short notice leave for any reason might not have a benefit, or be care-respecting, but that some things are determined to be more important because they arise out of obligations we value.

God. Although most religious beliefs may not be this demanding, it is reasonable to give more weight to beliefs that stem from these kinds of imperatives, such as an obligation to honour the religion, keep a promise or oath, to trust in another's authority, or to refrain from activities that harm others.

#### 8.2.1.4 Reflections on the cases

In the Druid case (2.8.1), we can see evidence for all three of these elements within Paul's worldview. His belief in animism, whereby there is an essential spirit in all living things, informs his day to day actions - his vegetarianism, career, and activities, making it seem very likely he has integrated this belief coherently into his worldview. Although animism is not a common belief in modern and 'Western' philosophies, from within his worldview, Paul's reluctance to undergo a transplant makes sense, as the transplant would violate something important about Paul's essential nature. The community leader in Paul's case disagrees about the acceptability of transplantation – such disagreement is common among Pagans. However, even in the presence or absence of community support, it is clear Paul believes he should reject transplantation as an option, and this arises from a belief which is held in an identity-giving way. It is difficult to see how someone would be prepared to risk death for something that was not critically important to the sense of self. Paul does not express his refusal as a form of promise or oath. However, nevertheless considers that such an action would be an invasion into his body, a violation of who he is, with profound spiritual consequences. His obligation is to keep himself whole. Paul's beliefs are of the qualifying type, the decision arises out of a coherent world view that is reflected by other choices he makes in his life, so, as far as meeting the belief criteria goes, Paul's request could be granted.

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In the Wiccan case (2.8.2), there are also elements of all parts of the criteria. In Katy's worldview there is a belief similar to Paul's that non-human animals should not be exploited, hence her rejection of animal products. However, Katy's belief about her care also strongly reflects the consequences of the belief 'As it harm none, do as thou will' (the Wiccan *Rede*) and the measure 'threefold return'. From within her worldview, it makes sense for Katy to believe she is being punished for a transgression of her duty, and that she should fully bear those consequences. She perceives a spiritual obligation to pay for her error.

Katy's initial reluctance to discuss her beliefs might be interpreted as her not really holding to them, or them perhaps being a reaction to the guilt that arises from 'magical thinking' (Matsumoto 2009 and thesis section 3.5.1). However, it is also likely that Katy has encountered hostility from others about her beliefs (Tejeda 2014 and thesis section 2.2) which might be preventing her feeling comfortable expressing them.

It might also be possible to argue that Katy has already borne the initial consequence, and that further suffering is not called for or warranted, or that Katy clearly did not believe in the *rede*, or she would not have cast her spell in the first place. Neither of these arguments would likely be well-handled unless they arose in discussion with someone similar to Katy in terms of her beliefs. This is a strong reason to include something like the religious interpreter, or at the least, an experienced member of the Wiccan community in discussions with Katy, before wondering if she lacks capacity or is not coherent in her beliefs.

In the third case (2.8.3), Karen (a Star Trek fan) and Simon, (an eclectic Pagan with strong Heathen influences), are competing to access a resource at a particular time. Although Karen is deeply passionate about the Star Trek convention and, indeed, considers it to be one of their most important projects, the unhappiness missing it produces in her is not based on a worldview-type belief. Nor does it arise from any kind of moral imperative

imposed by that belief. Karen loves and values Star Trek and conventions, but it is not a requirement of being a Star Trek fan that one must attend conventions.

For Simon, on the other hand, there is a matter of Oath-taking at stake. For Heathens in particular, and for many other Pagans, oaths are a form of significant vow-making (2.3.3) more akin to bonds of marriage than casual promises. Simon's commitment to hospitality and the shared honouring of the ancestors represents something more integrated with the worldview than mundane promises.

Whereas respect for their goals and projects is clearly something that indicates they should be accommodated as much as possible and not treated dismissively, Karen's request – as a preference – does not carry as much weight as a similar request from a Pagan, whose fundamental beliefs and obligations are at stake. A Pagan who places importance on a day such as a Solstice cannot simply treat it as an ordinary day, being asked to put aside plans to host a gathering with their kith and kin is being asked to violate important other-regarding obligations of hospitality and loyalty that arise from the religious beliefs, as well as spiritual obligations to respect the turn of the wheel and the symbolism of light returning to darkness. We might equally, if Karen was wanting to attend her own or best friend's wedding or a close relative's funeral for example, want to give priority to her case, recognising the important identity and social obligations around those events. If the two patients both had equivalently important religious-type beliefs (or neither had) in a similar scenario, and all other things being equal, then a tie breaking approach, based on a random method such as lottery, would be a justified option (as it is not possible to split the resource).

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# 8.2.2 Accommodating the belief offers a recognisable benefit to the patient that is not restricted to the biomedical sphere

The weighting system should also make explicit the positive outcomes of the request. If granting the request improves the patient's well-being and/or chances of recovery, this increases the weight to be given to the request. In chapter five (section 5.9), I discussed how religious and spiritual belief can have a beneficent effect on the patient, by improving medical outcomes and also making the patient's experience of illness less traumatic than it might otherwise have been. Beneficence is recognised as being a key value in healthcare; inclusion of this criterion would be a reminder that patients' religious beliefs can be invoked for beneficent as well as person-respecting reasons.

As a significant aim of medicine is to do good for the patient, any system that weights accommodations for religious belief should take positive impacts on the patient's wellbeing into account. Despite this, Buryska (2001) and Bock (2008) did not include a positive good in their weighting criteria, instead either looking at non-maleficence or incorporating beneficence into the original reason to give prima facie claims to religious accommodation. This revised criterion stresses the importance of how the patient themselves is situated regarding the harms or benefits of their beliefs, representing the *particular* approach required by CR.

It might seem obvious that we would not accommodate something that was harmful to the patient but that is what we already do with autonomy-serving informed refusals. Although refusal cases are built on moral authority over one's own body, the patient often choses on the basis that something is good for *them* even if it appears to be significantly bad. It is not only biomedical issues, such as physical suffering, which constitute harms: the setting back of life plans, violations of identity, loss of dignity, and existential suffering are also harmful.

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Supporting the competent patient's conception of the good is thus legitimate beneficence (Pellegrino, Thomasma 1988 p.117, Terry, Olson 2004, Bartel 2004).

A positive benefit criterion may also be of considerable benefit in cases that reflect undramatic, day-to-day incidences in healthcare, such as provision of certain foods and worship facilities. The accommodation of religious belief is not only for life-threatening scenarios.

#### 8.2.2.1 Reflection on the cases

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In the case of Paul, the Druid patient seeking 'special' treatment for his transplantation, granting his very unusual request has significant benefits in terms of his own health and in the allocation of resources to others. It is very unusual, but still leads to an obviously beneficent outcome for this patient. Additionally, Paul's 'non-compliance' can be seen not as an inability or wilful refusal to follow medical expectations that might make a transplant ultimately fail, but as the presence of an unrecognised barrier which could be sympathetically addressed. There is the potential for an achievable good health outcome- as there is when Jehovah's Witnesses are offered blood recapture technologies during and post-surgery, which means this criterion is met.

In the case of Katy's refusal of animal derived products, the situation becomes slightly more complex. Providing her with non-animal derived products might not provide the fastest recovery, but on the other hand, she would might otherwise refuse any treatment, which would clearly not be a good thing for her. On that count, it would be respectful of her wishes to be honest about the products (and surgical techniques) and also to provide alternatives, so this request would gain more weight on this basis.

Somewhat more difficulty is attached to her refusal of 'best care' in terms of surgery. Her refusal stems from a clearly grounded religious belief about acceptable behaviour toward 301

others (and the consequences of breaking those rules) and she is attempting to fulfil what she regards as a duty to suffer the consequences. Evidence suggests that where religious beliefs are associated with punishment and portray the patient as guilty of some kind of wrong-doing they are less helpful (Pargament, McCarthy et al. 2004 p.1202, Casey 2011 and thesis section 5.3). Thus, it is more important to clarify the belief that this is a required, or at least coherent duty arising from her belief. However, the idea of suffering trials to demonstrate repentance or to grow spiritually is common and has parallels in adopting a punishing training schedule to grow physically stronger; it could be deepening and strengthening Katy's sense of worth as a person to be willingly subjecting herself to a punishment. <sup>105</sup> What Katy's case illustrates here is the value of having someone knowledgeable about the worldview and metaphors of Katy's beliefs to be involved in her care, and identify where her request may, or may not, be good for *her*.

# 8.2.3 The request for accommodation is self-regarding, and does not require others to be harmed

As particularly discussed in chapters five and six, there is potential for religiously based demands to put harms on others. The weighting system therefore contains reference to potential harms, both to the patient and to others whether directly or indirectly. Both Buryska (2001) and Bock (2008) recognised that the onus is on the patient to accept the attendant risks of a particular course of action, not to impose them on others. As much as it is respectful of persons and beneficent to comply with religious requests, it is necessary to recognise that when there is no significant benefit (not only determined by a biomedical

<sup>&</sup>lt;sup>105</sup> This would be different, say, to someone paternalistically deciding that others ought to be made to suffer because it was ultimately good for them. People may *choose* to find something meaningful, but it ought not be valorised or expected.

benefit) to the patient and a high probability of harm or disadvantage coming to them or another we should down-weight the individual request. Persons are able to advance their own interests even at the expense of apparent harm to themselves, but care respect for their autonomy, and for that of others (who do not share the belief and do not want to be harmed by it) does not extend to allowing harm to come to others, as per Mill's arguments (1869). So, if the request being made is one that requires harm to be done actively to another person, or directly prevents another person receiving care from which they can benefit then an accommodation request based on a religious belief (or indeed any belief) should be down-weighted, in some cases severely. However, as all potential limits on another could be considered harms, the extent we hold this harm-avoidance line itself has to be balanced. Some redistribution of resources away from one in support of another is acceptable under CR, and some inconveniences or offenses (Feinberg 1988) to others are not significant enough harms to prevent accommodation. Nevertheless, it remains important that judgements about the worth or purity of certain persons violate CR's demand to extend CR to all persons.

The most obvious examples of harm being done to others for religious or cultural reasons is in circumstances where the patient is the child and the parents are pursuing a religious line, but this might also apply to adult others who are currently unable to give consent. The most obvious example of an indirect harm would be depriving another person of life saving treatment in exchange for a futile continuation of life support. Both of these situations are regarding incapacitated others and my focus is on patients with capacity, but it is worth

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restating. Religious claims for accommodation should be down-weighted where the request for accommodation is not made by the patient themselves.<sup>106</sup>

This, however, does not preclude others voluntarily taking harms onto themselves, such as though organ or tissue donation.

#### 8.2.3.1 Beliefs about the worth of others

Under care respect, we can recognise that patients may hold beliefs which are harmful and negative towards others, such as those which are racist, sexist, trans or homo-phobic, which can lead to abusive or violent behaviours. Although the harms caused when patients express these kinds of beliefs may seem inconsequential compared to medical needs, nevertheless we should not let people 'get away with' behaviours which may be bigoted or unacceptable (section 6.3.2). Persistent intolerant language and/or other behaviours are seriously damaging to the wellbeing of staff and other patients in the targeted groups. Thus, although care respect encourages us to see that people can only come from 'where they are' in terms of their experience and identity, accommodation requests should be in general keeping with the values of non-discrimination and tolerance within a public space. To an extent, then, care respect places a duty on patients themselves to give equal consideration to others regarding their personal beliefs.

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<sup>&</sup>lt;sup>106</sup> Beneficence might, on occasions, also require care and compassion to the friends, relatives and communities of those involved. Although the care of the patient takes priority, some things such as appropriate care of the deceased according to religious beliefs in the community to which they belonged is a form of beneficence to the families, at least where the patient and their close kin are known to have shared those beliefs. Thus, in some cases, if the patient themselves is neither harmed nor benefitted, the benefit to others can also be granted a weight. For example, in a case where the family wish to maintain futile, but unburdensome, measures for a brief period (Orr, Genesen 1997) there is scope to do so.

In general, it would be the case that requests based on opposition to a *type of person* should be down-weighted. This is similar to the literature around conscientious objection which specifies that the objection must be to the involvement in an act, rather than a judgement against categories of persons (Gerrard 2009 p.599). This was also upheld in law for a bakery that refused to make a 'support gay marriage' cake where Lady Hale (presiding) remarked 'the objection was to the message, not the messenger' (*Lee v Ashers*, UKSC 49 [2018a]).

However, there may be occasions where the benefit to the patient might outweigh objective concerns about attitudes to caregivers – for example, the provision of female staff for female patients (in other than emergency situations). For reasons of social justice, we are inclined to look more favourably on people who are already in a marginalised position, therefore we already accept that women may prefer to see a female member of staff for non-religious reasons and there are legitimate claims of beneficence to support it.

#### 8.2.3.2 Reflection on the cases

In Paul's case, his beliefs are self-regarding ones, although his initial erratic attendance could have had an impact on the care of other patients. Had he persisted in waiting until he needed emergency dialysis on further occasions and justified it by being entitled due to his beliefs, he would have been risking the health of others. However, Paul opts to refuse dialysis full stop. The most other-regarding element of the scenario is that Delwyn offers to become a donor for him, thus creating a scenario where Paul would benefit from harm to Delwyn (via the loss of a kidney and accompanying surgical risks). However, Delwyn is able to give or refuse consent; living kidney donation is an accepted (and successful) approach already, because of the benefits of a close match and a live donor. In that respect the Delwyn donating a kidney is not significantly different from other relative-donations and might well have been pursued as an option if Paul had not had the beliefs he has. This criterion is not

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intended to prevent people voluntarily undertaking potentially risky actions to benefit those they care about, but to prevent patients imposing their beliefs on those who cannot resist.

Paul's conditionality raises parallels with other instances where people seek to restrict to whom their organs go, or from whom they receive them (Wilkinson 2007, Moorlock, Ives et al. 2016), although I will not consider this here. Paul, however, makes no value judgement on the worth of the potential donor (or recipient), but determines it would be wrong for him to bring almost anyone else's essence into himself in this way. Unlike those who might want to still benefit from the transplant list but impose conditions, Paul has refused to go onto the list and thereby accept the consequences of his decision. Again, in this case, Paul meets the criteria on non-harm to others, supporting accommodation of his request.

The situation of Karen and Simon is interesting. Both patients are indirectly asking for something that has potential for harm -the risk of a less successful hand repair- to happen to the other. Both patients have stated they will accept the same harm of the less successful repair rather than sacrifice something else important to themselves. Whichever of the two is given priority the other will lose out.

If religious beliefs that bought about harms to others than the patient should automatically be down-weighted, Simon's stronger claim because of the nature of the belief, is neutralised by the fact that accommodating his request a harm will occur to another. However, meeting Karen's request would lead to Simon suffering the greater harm. Random allocation downplays the nature of Simon's reasoning and the importance of his belief, but upweighting Simon's request because of his religious belief could fall foul of the Equalities Act. Going back to the care-respect perspective, the nature of Simon's belief is identity giving and other-regarding in a way that Karen's is not. In this instance, where the differences between the cases is only the nature of Simon's belief, then we have a greater obligation to

accommodate Simon because of the underpinning nature of that belief and the potentially greater harm violating the identity would cause. There is very little in it, and the most ethical solution to this case is likely to rest on the attitudes of the staff being in keeping with CR.<sup>107</sup>

# 8.2.4 The patient accepts the consequences of their action and the medical situation giving rise to it

One of the requirements of the criteria is that the patient has a sufficient understanding of both the consequences of their course of action, and the nature of the medical facts that pertain to the situation (section 5.2). There are autonomy respecting grounds and legal support for this knowledge; the patient must be able to comprehend that they have a condition and that treatment X is considered as offering the best, or at least a reasonable chance at producing improvement Y (*Re C.*, 1 All ER 819 [1994]), and that refusing X or requesting something different has particular consequences for them (*Re T*, 9 BMLR 46 [1992]). <sup>108</sup> If a patient does not recognise that they have a condition or that a certain treatment is recommended based on medical experience, this is good grounds for believing the patient does not currently have the ability to make this decision about their care. The

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<sup>&</sup>lt;sup>107</sup> I am somewhat inclined to suggest that it would be useful to explain the full situation to the patients concerned. Perhaps both patients would be willing to explain their reasons and listen to the other's case, even if through a third party. Someone with very strong other-regarding obligations might factor this into their considerations once they realised what the cost would be to other people. An honest, consensual and *particular* conversation rather than one based around general principles, could, even if anonymised, put the patients back in control of decision making in a way that third party use of a random allocation would not. However, I am mindful that so doing involves other complex ethical considerations, such as confidentiality and privacy, which would need careful attention in practice.

<sup>&</sup>lt;sup>108</sup> In Re T, Lord Donaldson found that the life-threatening consequences of refusal of a transfusion were not clearly articulated to and understood by T. The lack of such information meant T's refusal did not clearly evidence a refusal in the life-threatening circumstance that developed.

patient needs only know this in general terms, and in ways related to the things they value such as mobility, family, freedom from pain and their life projects; a precise medical and statistical understanding is neither required nor likely.

Miracles, as previously explored (in section 5.2.2), present a difficult situation because it appears the patients do not believe the probability of death/ negative outcomes apply to them. The idea that some force will intercede and save them (or another) is taken as a sign of a self-centred or delusional rather than a religious belief, as miracles cannot be guaranteed. Criterion 1c, the moral obligation component, is also probably absent in the miracle-seeker. In my cases all of the patients exhibit this understanding, and miracles are not a particular feature of Pagan beliefs. However, I raise the issue because it is relevant to the application of the criteria to those religions where this is the case.

The choice that is presented in a situation with a miracle seeking but otherwise competent patient is that of forced treatment, itself problematic with respect to autonomy, versus the acceptance of the refusal or request. Patients in this position should have their wishes honoured, (to the extent it is possible) but the use of a religious interpreter as outlined previously, who is medically aware but also religiously competent, may be sensitively utilised here. Even where a patient's choice is not agreed with, their choice should be respected.

The situation is different for those deciding for patients who are not competent. People are generally free to accept a burden on themselves, but not to impose one on others.<sup>109</sup>

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<sup>&</sup>lt;sup>109</sup> Although Orr and Genesen (1998) responded positively to requests based on the idea of a miracle, they did so in the context of other criteria, such as beneficence to the family and the limited use of resources. Had the request been burdensome to the patient (had they been aware and suffering, for example) or had the resources not been readily available then accommodating the miracle belief would have lost some of its strength.

#### 8.2.5 It is possible to accommodate the belief.

In chapter five, I highlighted that we cannot be obliged to do something that is impossible (section 6.5). Furthermore, limits may be imposed by the inability of interventions to give a positive outcome, the availability of physical resources and staff, and emergency situations. Examples of these limits applying to aspects of religious belief might include a Jehovah's Witness' request for hyperbaric surgery where the expertise and facilities are not available, or allowing a patient to carry a metal ritual knife into an MRI machine, which would be too hazardous.

However, the fact that meeting a religious need is difficult does not mean it is impossible. Dillon comments:

the inappropriateness of always pulling out all the stops for everyone does not mean that it would be either inappropriate or impossible to approach others generally with more constrained, context-sensitive expressions of care respect' (Dillon 1992a p.131)

and that

difficulty does not entail impossibility (Dillon 1992a p.127)

Sometimes things are perceived as being 'impossible' in a health environment simply because it is unusual, difficult, or represents a deviation from the usual protocols or guidelines, rather than being genuinely impossible. Guidelines and protocols perform a valuable function in healthcare and should not be freely discarded, but the ability to find ways to accommodate a belief requires imagination and understanding, as well as flexibility. The process may be hampered within healthcare by differing attitudes to protocols. For example, adherence to targets and abiding by protocol is seen as over-ridingly important by 309

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management, as a key to professionalism by nursing staff, and as less important than personal skill and flexibility by doctors (McDonald, Waring et al. 2005).

In some cases, difficulties in meeting the requirements of a belief can be anticipated in advance, provided the decision makers are aware enough to recognise the possible difficulties. This is something that can be developed by approaching and listening to religious organisations and individuals before it becomes an issue, and by continuing to listen and be open to suggestions. However, if only a limited number of religious beliefs are recognised (by being part of a familiar or large demographic), smaller groups will continue to find themselves treated as oddities rather than people.

#### 8.2.5.1 Reflection on the cases

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In terms of the cases above, Paul's request meets resistance, in part because infection control procedures 'wouldn't allow it'. Given the highly restricted and infection - controlled nature of a surgical unit, observers are minimised to those with good reason to be there and they are similarly subject to infection control measures. Although it might therefore be *difficult*, someone suitably briefed and escorted could be admitted on the grounds that their presence is enabling the potentially life-saving operation to occur. There are, after all, examples of observers in a variety of hospital environments, such as medical student electives and observerships at various stages; those who may be interested in health careers; school students; and researchers (KDKA-TV 2011, Geiderman 2012, Griesar 2017). That is not to say that sympathetic alternatives should not be suggested, such as doing the purification before the surgery, but if they proved unacceptable, the presence of the observer is minimally intrusive for significant benefit. Thus, accommodating Paul's request *is* possible. It would be possible to find relatively small ways of mitigating the surgical team's concerns- for example, perhaps there is an existing member of the medical or nursing staff who follows a

Druid path who might be an acceptable candidate to Paul, someone already aware of how to behave in an operating theatre. This may be unlikely, so the next step would be to properly consider ways in which the priest could be admitted- guiding them through the process, the likely events of the surgery, the restrictions on movement, selecting the most appropriate moment to do the blessing to minimise disruption, and the procedure if there is a problem.

Katy's request for non-animal derived sources can, and should be accommodated, including clear disclosure of the ingredients of treatments and honesty where the ingredients are not known. There are additional costs involved, but these are not prohibitive. However, practically it is not possible to *partly* refrain from performing surgery (that is, to ask someone to deliberately perform it badly). I am reliably informed by a practicing hospital doctor that functional and cosmetic surgery tend to go hand in hand in injury repair. Whereas refraining from giving a blood transfusion is also a request for a doctor to do less than their best, transfusion only requires omission of a discrete action, surgery is a combination of multiple acts. It would only be possible to refuse or accept surgery, rather than make further specifications.

Due to the nature of the condition it is likely that multiple surgeries would be required over time, and she would need to give consent at each of these stages, rather than requiring a surgeon to perform a single operation badly. This consideration does somewhat leave that question unresolved by postponing it for a later time. However, this case does allow the luxury of time in which the patient might (or might not) change their mind. Because the potential harm to the patient it is appropriate to spend that time exploring their values. In the event the patient did not change their mind and refused further operations, the unusual motivation is not, of itself, adequate to consider that the patient is unable to make such a

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decision, and it would neither be justified or practical to force such operations onto the patient.

## 8.3 Taking people seriously

The five criteria above form the basis of a weighting system which could improve the ethical treatment of patients with religious beliefs that could impact on their care. However, support would need to be given in order to assure the questions of the weighting system are being properly answered and that the patient's spiritual needs were considered in later stages of their care. Under care respect, we should not be content to simply stand back. Our obligations to others require personal and organisational investment to ensure patients are treated in a way that adequately respects the person they are.

### 6730 8.3.1 Staff Training

CR involves both understanding the motivations of others and reflectively being aware of one's own lack of knowledge and preconceptions. To be a step closer to being able to CR a patient, staff need to be aware of the possible religious motivations; <sup>110</sup> aware that the religious and spiritual needs of patients are important; and at the same time recognise that it is inappropriate to assume that all people of a particular religion will behave in a particular way. It may not be immediately obvious that a request is coming from a position of religious

<sup>&</sup>lt;sup>110</sup> A brief understanding of some key elements of Paganism, for example, would enable staff to recognise important symbols and use this as a starting point of non-judgemental discussion – for example – 'I see you are wearing a hammer symbol, does it have religious significance for you?'. Reinforcing that it can be inappropriate to handle some religious objects could also encourage staff to habitually ask – 'am I able to move this for you?'

belief, or indeed it may look on the surface that a request or action is coming from such a place, in whereas it actually is not.

To achieve this, staff need to be familiarised during their early healthcare education and Continuing Professional Development (CPD) with these outward manifestations of belief. My experience of working in medical education (with medical and dental students) is that although students are told that they must respect beliefs, little time is found in the curriculum for exploring how or why. Ellis and Naranasamy note:

there is consensus that spiritual care within nursing practice remains fairly underdeveloped in comparison with other elements of care... [contradicting] basic nursing ethics, which state that every nurse is responsible for ensuring the provision of spiritual care to patients (Ellis, Narayanasamy 2009 p.888).

The situation is similar in mental health nursing (Morgan, A. 2017), where spirituality and religious beliefs are recognised as important, but nurses feel ill equipped to discuss this with patients. In medical education in the US, there does not seem to be much training in the area either (Rasinski, Kalad et al. 2011, Puchalski, Christina 2006, Koenig, Harold G., Hooten et al. 2010). In the UK, where the GMC states '[w]e recognise that personal beliefs and cultural practices are central to the lives of doctors and patients' (General Medical Council 2008), Moynihan's study identified that only 34 % of those healthcare professionals

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<sup>&</sup>lt;sup>111</sup> A recent case that illustrates how a situation can be wrongly attributed to religion is the recent instance of Jehovah's Witness parents removing their child from a UK hospital. Several commentators in my personal sphere took this to be an illustration of how religion was being used to harm children. The actual situation was instead that of desperate parents who had been told they could not receive a particular treatment and had absconded with the child to seek treatment elsewhere. Their actions may have been inappropriate, but the motivation was not a religious one, but instead one of parents desperate to heal a child.

questioned had received formal training in spirituality and health (Moynihan 2008). Culatto and Summerton (2015) identified that although undergraduate spirituality and health teaching was generally (but not always) seen as valuable, it tended to be integrated rather than specifically covered, something that was not always an effective method given students' preferred learning methods (Culatto, Summerton 2015 p.2270). It seems apparent there is a deficit in training for issues of spirituality and religion in healthcare. The area is so important (bearing in mind that many beliefs, even those which do not have a religious element, perform the same identity defining, value shaping role religious beliefs play) that more training seems to be a requirement.

My own experience in medical education has involved seeing a lot of students consider psychosocial and spiritual elements of the curricula as 'fluffy stuff', less important than the technical and the physiological, <sup>112</sup> a disdainful attitude actively fostered by some members of the teaching team. In some respects this is the 'hidden curriculum', the unwritten 'here is how we really do it' identified as damaging to medical education (Browning, Meyer et al. 2007).

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To treat people with CR requires strong empathy skills, to see someone as the person they are. Hojat, Gonnella et al. (2003) express this type of cognitive empathy as 'the human capacity to understand the views, experiences, and feelings of another being without intensive emotional involvement. To be understood is a basic human need' (p. 27). However, a loss of empathy during medical training and residency (as well as for other HCPs) is a known difficulty (Batt-Rawden, Chisolm et al. 2013, Browning, Meyer et al. 2007). Such

<sup>&</sup>lt;sup>112</sup> This is not to claim that technical competence and understanding are not crucial to the practice of medicine and should not be the majority of pre-qualification training, but that the devaluing of other topics is a significant problem.

empathy is 'a cognitive attribute that involves an ability to understand the patient's inner experiences and perspective and a capability to communicate this understanding' (Batt-Rawden, Chisolm et al. 2013 p.1171). Something which adopts a relational approach to pedagogy might be deeply relevant to CR's care ethics roots, one such proposal has been Browning, Meyer et al.'s 'Program to Enhance Relational and Communication Skills' (2007).

There are too many religions for students in healthcare to understand the intricacies of all of them, but if students were able to maintain an empathic approach throughout their practicing careers, at least part of the difficulty – of not taking people seriously- could be ameliorated. That said, key facts about those religions an HCP is most likely to encounter should not be removed from curricula. They should neither be considered exhaustive, nor should alternatives be considered as weird deviations.<sup>113</sup>

However, the introduction of further training has practical consequences; for example, whether elements of curriculum should be removed or reduced to make way for it, or whether such training ought to be a voluntary or specialist elective. If the latter, then it could be something health organisations should actively recruit for to ensure there are enough staff available who have such training. Space prohibits full consideration of the implications for training, but without spiritual dimensions of care being properly being addressed, Pagans and patients with other religious or spiritual beliefs may be neglected in terms of being given care respect as particular persons.

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<sup>&</sup>lt;sup>113</sup> Medical education in particular is not socially diverse in the UK. Most applicants are white and from the highest socioeconomic groups, which has consequences for how well doctors relate to those unlike themselves (Kumwenda, Cleland et al. 2018, Guiton, Chang et al. 2007).

#### 8.3.2 Taking a Spiritual History

Spiritual assessment is described by Cadge and Bandini (2015) as 'the process of evaluating someone's spiritual needs and resources and addressing those needs in the context of clinical healthcare' where 'spirituality [is conceived as] broader than religion, concerned with meaning-making, human connection and community connected to or quite apart from a sense of God or the sacred' (Cadge, Bandini 2015 p.430). The term spiritual history is often used to refer to a shorter, screening type approach (Koenig, H. G. 2004) with full assessment reserved for those in spiritual crisis (Cadge, Bandini 2015 p.435). By taking a spiritual history, the health care provider can establish the role that religion (and other spirituality) plays in the patient's life, which can potentially help to answer the questions posed by the weighting system alongside showing respect for the person.

Early spiritual assessment tools were primarily developed by nurses and chaplains and have developed over time, throughout which there has been increasing recognition that spirituality is a wider concept than religious beliefs (Cadge, Bandini 2015 p.435). These tools were often developed separately in clinically distinct areas, particularly psychiatry and palliative care, but more recently they have been developed for wide application across a variety of specialisms. Multiple assessment/history tools are available, often named mnemonically to aid in their deployment (Koenig 2007), such as FICA, FACT, SPIRIT, and HOPE (Hodge 2006, Anandarajah, Hight 2001, Larocca-Pitts 2008, Maugans 1996, Cadge, Bandini 2015)<sup>114</sup>. All aim to identify whether the patient has important religious and/or

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<sup>&</sup>lt;sup>114</sup> FICA- Faith or belief, Importance and influence, Communities of support, Address these issues SPIRIT – Spiritual belief system, Personal spirituality, Integration with spiritual community, Ritualised practices and Restrictions, Implications for medical care, Terminal events planning. FACT – Faith and or belief, spiritual histories, Active (available, accessible, applicable), Coping (and conflict, comfort, concern), Treatment plan. (ctd 317)

spiritual beliefs, whether these may impact their care, the positive benefits the patient gains from them, and whether the patient wants to explore and discuss such beliefs during their care.

6820 There has been some concern that health professionals becoming involved in the religious and spiritual needs of patients is unwise (Cohen, Wheeler et al. 2001) which had led to a negative impact on preparedness and ability to discuss spiritual matters with patients (Chibnall, Duckro 2000, Chibnall, Daly 2006). However, many patients consider it important for professionals to be able to raise spiritual issues in an appropriate way (Yardley, Walshe et al. 2009, Jackson, Gray et al. 2008). Concerns often focus on the danger of the beliefs of health professionals being used to pressurise or even convert patients, and the inappropriateness of straying into the private and sensitive domain of spirituality and religion (Culatto, Summerton 2015 pp.2271, 2274). Sulmasy notes that whereas it is legitimate for health professionals to worry about 'proselytizing of patients or the replacement of wellestablished, scientific Western medicine with quackery' (Sulmasy 2002 p.31) it is not 6830 legitimate to ignore patient's spiritual needs as a result. However, as Berlinger (2004) observed, what mattered most to her friend undergoing cancer treatment, was a mistake with her medication and the shortage of staff (Berlinger 2004 p.692). It is therefore inappropriate to assume that all patients wanted was a spiritual element of their care, but the standard delivery of a spiritual history identifies those who do not want further discussion alongside those who do. Much as a medical history is intended to find out which,

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**HOPE-** Sources of Hope, meaning, comfort, peace and love, Organised religion, Personal spirituality, Effects on medical care.

if any, medical treatment is appropriate, a spiritual history is intended to find out which, if any, spiritual dimension of care is required.

Beyond the immediate value to the patient, spiritual histories can have a role to play in developing a trusting relationship with health professionals, this trust making patients more likely to be involved in their care and more likely to volunteer information, leading to better outcomes (Safran, Taira et al. 1998). The spiritual history enables the patient to be brought to attention of chaplains or other specialists if required, and the accumulated spiritual histories of multiple patients could assist in future planning for health provision based on the reported values and needs of the patient population. Through the use of spiritual histories, the factors that make up ethical dilemmas and difficult decisions become more transparent.

Because of the way in which some beliefs shape a person's identity and their worldview, as discussed in chapter three, it is difficult to imagine being able to offer care respect without knowing and caring about this aspect of the patient as a person. Understanding a patient's beliefs and motivations is a critical part of care respect. HCPs are trained in question tools designed for diagnosis and treatment of medical conditions, and adding spiritual needs reinforces the patient as a particular person. Their routine use would help make it clear that the patient has meaning as the person they are. To paraphrase William Osler, 'listen to your patient, she is telling you who she is' (Osler 1905).<sup>115</sup>

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<sup>&</sup>lt;sup>115</sup> Often attributed to Osler, is the expression "Listen to the patient," because the patient is "telling you the diagnosis." Additionally, Osler commented, 'it is as important to know what kind of a man (sic) has the disease, as it is to know that kind of disease has the man' (Osler 1905)

#### 8.3.3 Religious interpreters

When patients and the medical team conflict over the best course of action, it may be a case of conflicting values, situations in which the worldview of the medical team and the worldview of the patient do not share the same priorities and metaphors. Negotiating this scenario according to a CR perspective requires some way of communicating between these two sets of values to identify the beliefs that deserve weight. Buryska suggested there was 'an obligation to be accurately informed concerning the teachings, values and practices of the relevant communities' (Buryska 2001 p.122). There are many thousands of potential communities, and whereas it is important for HCPs not to make assumptions about a particular belief, it would not be practical for an HCP to be aware of them all.<sup>116</sup>

As mentioned in chapter six, Orr and Genesen (1997), and later Bock (2008) draw on the idea of a 'religious interpreter' in cases where there is conflict between the patient's religiously motivated decisions and the medical team's desired approach. A religious interpreter is a mediator who is able to see and understand both perspectives and communicate meaningfully between them. As such, they could play an important role in ensuring the needs of those with Pagan (or other) beliefs are respected and appropriately met.

Orr and Genesen state that 'where no one on the team belongs to the same or similar faith community, it may be helpful to involve a "religious interpreter" much as one would use a "cultural interpreter", and suggest that this could be 'a hospital chaplain, the patient's own clergyperson or spiritual advisor, or some other individual familiar with the specific beliefs

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 $<sup>^{\</sup>rm n6}$  It would not be impossible to dispel some of the most frequently occurring misunderstandings, however.

which have led to the conflict' (Orr, Genesen 1997 p.146). In earlier work on cross cultural medicine, Orr noted that '[n]o individual clinician can be familiar with the language, customs, and beliefs of the myriad cultures represented by patients' (Orr 1996 p.162). Family members, family pastors and local professionals are possible sources of cultural information, but they may not be able to understand or relay the medical team's position. Orr and his collaborators adopt a humble and deeply particular response to culturally formed ethical dilemmas, stressing the value of time, understanding and compromise from a position of reflectiveness about one's own biases (Orr 1996 p.163). A religious interpreter, in a similar way, can articulate the patient's values to the medical professionals, identify 'fox hole' religion, and negotiate compromise (Orr, Genesen 1997 p.146).

Bock conceives of the religious interpreter in a slightly different way, making 'the test of a religious interpreter' a gatekeeper to medically valid religious beliefs (2008 p.439) and suggesting the interpreter could fulfil many responsibilities, including the following:

- 6890 (1) to support the patient and the family,
  - (2) to help articulate the patient's belief to the physician and
  - (3) to help articulate the physician's point of view to the patient (Bock 2008 p.439).

Bock suggests that the hospital chaplain or social worker might fulfil the role if they have sufficient knowledge, the family priest or equivalent if they will talk to the medical professionals, or, possibly, in the case of rare sects, someone from the academic community. He places the interpreter as a mediator and third party, capable of also understanding if there is a fox hole element to the belief, placing long held beliefs as weightier than death-bed conversions. Bock also identifies a concern that followers of the particular religion

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involved might be unable to be impartial or neutral because of their own commitments but concludes that being religiously affiliated is no necessary bar to being able to do this role. Orr identifies, where Bock does not, that subscribing to the prevailing 'Western' worldview is also likely to be a barrier to impartiality (Orr 1996).

Bock, by making the RI an integral part of his criteria, gives the interpreter a pivotal kind of role, in which the interpreter can determine whether a patient's belief is of the right sort to be accepted as having weight. Although I agree on the importance of the patient's beliefs being of the identity shaping, life-reconciling type, the interpreter is just one means of establishing that, not the only way. As such, I treat interpreters as an aid to interpretation, not as gate-keepers. That said, where such interpretation is required, the interpreter should be as respected as other people involved in the patient's care, not side-lined as 'fluffy stuff'.

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The religious interpreter, rather than being a job title (although it could be), is a role that could be performed by a variety of people. Because of this, the quality of interpretation varies – as is the case when patient family members need to translate languages for HCPs but lack the medical terms. Hospital chaplains (and those in similar roles) have the advantage that they are trained to work in a hospital, becoming familiar with the medical environment and language as well as the pastoral and spiritual needs of the patient population. Family members or family spiritual advisors may not understand the context or language of medical care. However, the ability to understand, advocate for, and negotiate with patients with beliefs that seem unwarranted or odd is a critical role if the values of individual patients are to be given care respect. Orr and Genesen (1997) and Sulmasy (2002) also point out that a doctor (or other health professional) cannot learn the full details of all the religions and cultures they may encounter. A familiarity with the most common beliefs and culture of the area in which the HCP works is important, but unlikely to be enough when deep values

conflict. This is a familiarity that hospital chaplains often have; a good reason for hospitals to continue to fund them, just as they would pay for a translator to communicate with patients who did not speak the local language.

There are not, however, chaplains of all faiths in all hospitals, and the other solutions may be less than ideal; for example, academic experts may not be welcomed into the patient's reality or be versed in the medical experience, and families are often reluctant to work with social workers (who themselves are already massively overloaded). However, it might also be possible for people to be trained into the interpretive role fulfilled by chaplains, which did not need the (also valuable) elements of religious ministry such as officiating at ceremonies. Health professionals with religious beliefs might benefit from this being an area into which their role could expand (appropriately remunerated and balanced with clinical duties), as well as those with counselling training or lay people being trained into it. As an advocate for patients and their families, RIs seek to understand and present a faith or belief perspective as valuable and meaningful to other people involved in their care. As an advocate for the medical team, they present the goals and beliefs of the medical team to the patient on the patient's terms.

At the moment, there is the possibility that patients with Pagan beliefs are not being heard or seen in relation to the intersection of their beliefs and their healthcare, which means they are not being treated with care-respect. There are very few Pagan chaplains to fulfil the role, and although this does reflect the relatively small numbers of Pagans calling on their services, does also mean that Pagans may well find it hard to find such a person if they need one. The time available for health professionals to spend on these conversations is legitimately limited, as they also need to spread their time among many other patients with medical needs. Therefore, someone who can fill the need for a religious interpreter -whereas

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not removing the need for due consideration of such matters by medical professionals- is an important element of meeting the religious and spiritual needs of patients.

### 6950 8.4 Concluding remarks

The five criteria presented above represent a refined form of previous 'weighting systems', utilising earlier work in the thesis on the nature of belief, ethical and care respect considerations in health care and justifiable limits on accommodation. Beginning from the assertion that religious type beliefs have a weight, each of the criteria points HCPs at factors to be considered when ethically responding to accommodation requests.

The nature of the belief criterion, through the three parts, represents understanding the role that the belief plays in the patient's worldview. The importance of certain types of belief, the significance of worldviews to the identity of persons we seek to respect, and a recognition of the importance of moral obligations, combine to gives this ethical weight to patient requests based on such beliefs. By requiring that the belief is the patient's own belief, concerns that religious communities might be limiting the patient's autonomy are ameliorated, as well as ultimately recognising that community is not the essential part of why we accommodate religious belief, but the nature of that belief in the person themselves. Criterion two makes it obvious that the request must give a benefit to the patient. Such a benefit may not necessarily be a medical one, but according to the patient's values, they are nevertheless gaining something important and meaningful if the request or refusal is accommodated. Although the literature discussed in chapter five demonstrates that religious beliefs have important impacts on beneficent outcomes, and are often cited in support of accommodating beliefs, the previous weighting systems have not made this explicit, and as such, proper attempts to discover what the patient gains from the request

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may not have been fully explored. Also, as many interactions between healthcare and patient beliefs take place in understated ways, such as the need for worship spaces and ritual, specific diets and simple acceptance, this criterion gives weight to everyday requests.

The third criterion relates to the belief being about what happens to the person holding the belief, rather than enabling decisions to be taken on behalf of others, decisions which might be harmful. It builds on the medical value of non-maleficence, and on the concept of autonomy being about making decisions for oneself. It recognises that in some situations, the request would lead to an unwarranted harm being inflicted on a person who may not share the patient's values. The criterion also helps counter requests for accommodation that devalue certain categories of people (e.g. BAME persons, homosexual persons, transgender persons), as such devaluing is harmful and goes against the underlying principle of care respect.

The fourth criterion requires that the patient must understand their medical circumstances. Although a nuanced grasp of medical statistics is thankfully not required, it is too important to the decision-making process for the patient to not recognise the reality of their condition, and that the HCP's proposed course of action would, if pursued, likely result in the best *medical* outcome. The patient should be given opportunity to come to terms with the condition (where possible) and requests for second opinions and the like should not be interpreted as a rejection of medical realities.

The final criterion simply requires that the requested accommodation is possible. In chapter six I discussed that impossible things cannot be an ethical requirement; however, serious attempts should be made to explore the possibility of accommodation. Habit and custom can make things look impossible, when, in reality, an accommodation could be made. The

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criterion functions as a reminder that accommodation is not infinite, but that there are grounds for exploring options.

These five criteria represent an improvement on previous weighting system attempts, as they refocus attention back on the patient's identity as a person with meaningful beliefs and values and on the gains the patient makes from the accommodation of those values. Paganism is poorly understood in the mainstream and may not register as 'proper' for some, even those who are supportive of the more well-known religions. However, a lesson of care respect is that obligations to accommodate belief do not derive from respect for well-established religions, but from respect for the particular person. At the same time, they acknowledge legitimate limits on the accommodation that can be offered and expected in order to preserve patient autonomy and the value of medical non-maleficence.

To properly care respect Pagan patients, professionals also need to have adequate training about the importance of belief systems. Research and experience suggest that religious and spiritual care is not perceived as being adequately covered in medical and nursing education, and this may be seen in the awkwardness of care providers around this issue. The essence of the care-respect perspective is to give a value to the things that patients perceive as of importance and value to them to properly care about and respect them as a person. Thus, further training that helps HCPs understand religious perspectives leads to greater ability to care for diverse patients.

A crucial element of giving proper ethical weight to identity giving religious beliefs, and in so doing taking a care respect approach, is to have a way of identifying and working with those beliefs. Although it is advisable for HCPs to become familiar with the religious beliefs of their local patient populations, and to be open and accepting of the idea that religious values are meaningful and relevant for patient care, there are considerable time and resource

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pressures which mean the time available for discussion about beliefs with patients is limited. The routine use of spiritual histories, and the presence of someone able to act as a religious interpreter, are both ways in which this can be achieved, without all health professionals needing to become theological experts.

The spiritual history, in whatever form it takes, opens the door to the discussion of the patient's beliefs and values, and makes the identity of *that particular patient as a person* a prominent part of their care. Admission forms may include a simple descriptor of a religion or no religion, but given the variety that exists within a single belief system, and the variable depth of adherence, it can only be of the barest use. As well as performing the immediate task of caring for that patient at the time, such histories are likely to also provide a valuable resource for future planning of services, and in future care of the patient. Some patients may find them unnecessary or unwanted, and they should not be pressured to participate, although the framing of the questions might help with that – some may reject religious or spiritual history but might be comfortable with 'what kind of things matter to you?'.

The religious interpreter is a person who takes on a mediatory or sometimes advocacy role, able to bridge the gap between the values of the medical team and the patient or family. In many ways this role is part of what chaplains already do in health care, combining a knowledge of the patient's beliefs with an understanding of the medical environment. However, chaplains are not available for all religions and Pagans may struggle to find someone who can perform this role when needed. Family, friends or the patient's spiritual advisors can assist in providing knowledge about beliefs where there is a conflict, but because they may not also have an appreciation of the 'medical language' they may be less effective. Given the importance of providing someone who can interpret between the medical profession's practice and values, and those of the patient, I tentatively suggest that

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it might be possible to specifically train people to do this pastoral role, in order to properly care respect patients with religious (and indeed, other) beliefs.

Greater professional education, spiritual histories and the involvement of religious interpreters can enhance the care respect approach to accommodating the religious beliefs of Pagans in a healthcare setting.

### 9. Conclusion

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The conflict between patients and health professionals over the role of religious beliefs in the provision of healthcare is a persistent feature in medical ethics. The literature frequently refers to one or another concept of respect for autonomy or respect for persons (Beauchamp, Childress, 2012, Bratman 2003, Charland 2015, Dworkin 1988, Frankfurt 1971, Hyun 2001, Kant 1979, May 2005, Miller 1981, Sheila A.M. McLean. 2009) as a means of permitting accommodation of religious beliefs. It generally uses conceptions of incapacity, justice and non-maleficence (Beauchamp, Childress 2012, Hyslop 2017, Clarke 2000, Savulescu, Momeyer 1997, Savulescu 1998a, e.g. Sokol 2009) as a means of limiting them. When such issues cannot be successfully mediated by those within healthcare and the case particularly concerns issues of liberty and harm-to-life, the law may become involved, involving frameworks of rights and duties (Human Rights Act 1998. 1998, The Equality Act 2010, Mental Capacity Act. 2005), or case law on medical decision making (Re T, 9 BMLR 46 [1992], Re C., 1 All ER 819 [1994], Bland, AC 789 [1993]).

Professional guidance (Nursing and Midwifery Council 2015, General Medical Council 2009) and the constitution of the NHS (NHS 2015) highlight the importance of treating those with religious beliefs with respect, even when conflict of values arise; many works also stress how important spirituality and religion are in a patient's life (e.g. Brady, Peterman et al. 1999, Gordon, Mitchell 2004, Delgado 2005, Narayanasamy 1999, Sulmasy 2002). Nevertheless, there is evidence (particularly discussed in chapter three) that some of those with religious beliefs, who are a becoming a minority within a secular population (Office for National Statistics 2013, Harding 2017), must fight for the appropriate respect within healthcare.

The novel element of the thesis is the application of 'care respect' (CR) (Dillon 1992) to the question of accommodating religious beliefs. CR for persons addresses feminist concerns about the primacy of rationality (e.g. Gilligan 1993, Little 1996) and the neglect of 'caring about' (e.g. Noddings 1986, Held 2014) others in terms of ethical theory. Nevertheless, it also retains a commitment to respecting and taking seriously (Buss 1999) the particular ends of others even if their values differ from ours. Although care ethics and revised versions of relational autonomy have been applied to healthcare, this fusion concept has not. The CR approach is to be interested in helping others achieve their ends, adopt a reflective position on one's own beliefs, to make sincere efforts to understand the other, and to see persons as more than incidences of the category 'person'.

CR does not entail that 'anything goes'; there are ethical grounds within CR for not acceding to all religiously motivated requests. Care respect supports limits that should be imposed when a request fails to respect others. For example, if the request causes harm to a minor or third party, if resource limitations make fulfilling a request impossible (both chapter six), or it is not is not voluntary (chapter five).

Religious beliefs form a critical aspect of the identity of those that hold them. Although some have very generalised beliefs, for those who hold them in such a way as it causes conflict in healthcare, the patient's way of life, their values and meaning are shaped by these beliefs. They 'fill out' the person, occupying a central place in a worldview that embraces a transcendent element (Wreen 1991). However, the worldview of modern UK healthcare (and much of the 'Western' world) is predominantly secular, so the different prioritization of values in the different worldviews leads to conflict (Benjamin 1990). The approach to religious beliefs and accommodating them within healthcare ought to be based on this understanding of the centrality of such beliefs to the persons that hold them. Importantly,

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the nature of these important 'life-reconciling' beliefs is not dependent on size or tradition (or indeed on being religious). Thus, the modern Paganisms ought to be treated in the same way as more mainstream beliefs.

Most cases previously discussed in the literature are those of adherents of either a branch of Christianity or a branch of Islam. As these are statistically larger faiths, it is not surprising that they are more often in contact with healthcare. However, the commonalities between these large, traditional religious institutions -the presence of a single male God, a priestly hierarchy and a holy book- mean they are also more recognisable.

In a new critique of systems designed by Buryska (2001) and Bock (2008) to justify the making or limiting of accommodation of religious beliefs, I demonstrate that such systems rely heavily on the example of large Traditional faiths. This makes them a poor fit for ethically accommodating less mainstream religious beliefs. The importance of patient wellbeing, which is closely linked to identity and chosen life, was not explicit in these systems. I therefore propose an alternative which better reflects the ethical concerns of CR and improves the approach to accommodating the religious beliefs of patients.

Potential areas for further research are empirical studies of Pagan beliefs around healthcare and their experiences within it, extension of the weighting systems to healthcare professionals (which may require a greater consideration of integrity re. professional duties) and the application of care respect to other groups who may also suffer from difficulties within healthcare systems.

### 9.1 Religious beliefs are important

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Pagan experiences suggest that the beliefs of modern Paganism, and the religious and spiritual needs of modern Pagans, may be treated differently from those belonging to folk 330

from the larger religions. Paganism's diversity, relative newness, and difference in approach to the more familiar Abrahamic faiths could count against it. Noting this, I returned to basics and ask what it was about religious beliefs that prompted conflict between healthcare professionals and patients in the first place.

Religious beliefs vary extensively between religions, although there are some commonalities. In this sense religions have a family resemblance to each other, even if they are very different. Any particular religion may be described in terms of its distinctive beliefs, rituals and symbols. However, a range of different religions, and thus religion itself, can be understood as the beliefs, behaviours and morals through which adherents connect and interact with both the transcendent and the mundane.

The transcendent does not need to be a discrete deity of the familiar monotheist God type, the *Nirvana* of Buddhism, the many *Kami* of Shinto, and the *Awen* of Druidry are also transcendent. Critically, the presence of the transcendent inspires beliefs and behaviours which strongly impact on the believer's way of life and moral code. These beliefs and behaviours may involve ritual, iconography, forms of worship, and other community activity, which perform the important role of connecting the believer to the transcendent and to others. One of the ways they do this is by being integral to a worldview (Benjamin 1990, Smart 1995, Sire 2004, DeWitt 2010).

Some worldviews are religious; for example, a Methodist worldview, a Hindu worldview, a Druid worldview. Others are secular; for example, a Marxist worldview, a scientific worldview, a feminist worldview (Smart 1995). With their worldview, people see the world, interact with it, understand their place in it, determine their priorities, and find answers to life's fundamental questions (Benjamin 1990). Thus, religion is a multidimensional concept fundamentally to do with the identity and actions of human beings. The importance of a

worldview (whether religious or not) in shaping identity and way-of-life is ultimately crucial grounds on which we can and ought to accommodate religious beliefs in healthcare.

Although less familiar in the UK than Christianity, the rituals and beliefs of Paganism perform the same kind of functions as those of other religious affiliations (see chapter two). Although Paganisms often lack the behaviours and dogma that are associated with religions like Christianity (Harvey 2011), they qualify as a religion even without these, having their own transcendent, behaviours, symbols and ensuing connections. A Pagan's way of life develops from a worldview that answers the same questions as other worldviews- questions such as the existence of a Deity, deities or similar force, the relationship between humans and the rest of the planet and what is the moral way to behave towards others. Pagan beliefs shape the believer's ends and motivate them to act. Therefore, the beliefs held by Pagans are identity conferring, obligation giving, and life-reconciling beliefs. As such, the modern Paganisms are deserving of the same attention previously afforded to the others in the ethics literature.

Paganism's relative absence from the healthcare literature means it is useful for reexamining approaches to accommodation of religious belief. Using Pagan examples highlights key areas of ethical interest and tests the effectiveness of proposed methods for accommodation.

## 9.2 Religious beliefs impact on healthcare, and religious believers may be poorly served

In the UK, healthcare is normally provided within the secular environment of the NHS. The NHS relies on modern, evidence-based approaches to treatment. However, a patient's worldview and that of those caring for them can differ wildly, leading to conflicts over the

relative importance of different aspects of that care. This interface between religious beliefs ranges from cases where the religious belief has a negative effect on health –and may even lead to death- to cases where religion is a positive benefit to patient wellbeing (see chapter three). Because of this, there is a need to find ways for the NHS to accommodate (make room for) the views and needs of patients with differing worldviews. The NHS principles recognise these points of conflict and seek to address them- patients should be treated with 'respect, dignity, compassion and care' (NHS 2015 p.3) and without unlawful discrimination on the basis of their religion (among other characteristics) (NHS 2015 p.6).

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Religious beliefs held by patients and practitioners have the potential to be negative. Physical and mental harms may take the form of self-imposed harm through refusal of care (Miller 1981, e.g. Wreen 1991, Tatham, Patel 2014), the imposition of the will on others who cannot defend themselves (Gomella 2012, Orr, Genesen 1997), exclusion and fear of judgement by professionals (e.g. Barfoot 2015, Hamilton, Levine 2006, Hathaway 2006) and the consumption of resources needed elsewhere for more clinical demands (Savulescu 1998a, Savulescu 1998b). Conversely, however, religious beliefs held by patients and practitioners have the potential to be good influences (e.g. Astrow, Puchalski et al. 2001, Baldacchino, Draper 2001, e.g. Terry, Olson 2004, Royal College of Psychiatrists 2013). These benefits could be the providing of critical moral support in times of acute stress, making sense of the experience of illness, providing a sense of identity, encouraging caring behaviours and assisting in the recovery process.

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Religious beliefs can also impose obligations on the believer that may be hard to meet in the hospital setting. These include carrying out religious practices, wearing particular clothing or items, eating a particular diet, or interacting with a different gender (e.g. Samra 2011). These are events with *daily* impact. Importantly, patients also fear reactions to their religious

beliefs, arising from experience of ignorance, discrimination and bullying directed towards people like themselves. Simple ignorance of, and disvaluing of, religious beliefs by health professionals is insidious. It may be less dramatic than a life or death case, but the potential to alienate patients from the organisation they are coming to for help has severe consequences for their wellbeing.

A fully permissive, 'do not question' approach to religion in healthcare has the potential to open both patients and staff to the harms suggested above, allowing religious beliefs to dictate action in the face of limited resources, the coercion of people by others, through intractable suffering and sometimes to the point of death. However, to exclude religious beliefs from the equation entirely is to have a health service focussed only on the medical model of disease and ignore the benefits such a belief brings, as well as doing a disservice to the identity of believers. Religious beliefs are still important to individuals, and the NHS claims taking account of these needs is required. That patients are still encountering challenges in having their religious needs met, particularly in terms of respect and values, demonstrates the need for revision of the current approach.

# 9.3 Care Respect addresses important aspects of the person which support the importance of religious beliefs

Something prevents healthcare professionals simply applying evidence-based treatment to patients regardless of the patient's wishes in the matter. Given that the NHS urges 'respect, dignity, compassion and care' (NHS 2015) towards patients and their families, this suggests some ethical features of accommodating religious belief. Although religious beliefs are not people, they are held by people in a very critical way; when someone asks for their beliefs to

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be respected, they are asking for they themselves to be respected – a feature not only found in religion but for humans in general.

According to the recognition respect conception (Darwall 1977), we owe persons respect because of the intrinsic qualities of persons. Broadly, this is a recognition respect of their cognitive qualities and/or moral agency (Warren 1997, Beauchamp, T. L. 1999); meaning we respect others as bearers of rationality who ought to be free from interference. However, there is a risk accompanying the dependence on rational/cognitive traits, which is the idealisation of such traits (e.g. Stoljar 2000, 2018). This may exclude people from proper respect by being overly demanding. The ability of something to suffer harms, and to have an interest in avoiding harms, (including physical suffering, violations of self and identity and the setting back of our interests and our ends) (e.g. Singer 1976, Warren 1997) ought also to be a source of obligations. The *vulnerability* of others to our actions ought to inform our respect (and our care) (Dillon 1992a). The concept of care ethics (e.g. Noddings 1986, Held 2006), a feminist approach to persons, requires recognition of the unique identity of the particular, and adopting a position of responsibility towards others.

The two conceptions, respect and care, are fused in the concept of care respect, proposed by Dillon in 1992. CR envisions a kind of respect that is attentive to both the qualities of persons (as rational entities and as feeling beings), as well as the individuality of people. It is not possible to properly have recognition respect, without recognising the individual's concrete particularity. Religious beliefs are one source of particularity, thus a respect that does not take seriously the religious beliefs that are features of the morality and identity of those who hold them, fails to properly respect them. Both respect and care are integral to the ethos of the NHS, therefore, I adopt CR as an approach to accommodating religious beliefs in healthcare, in a novel contribution to the literature.

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Respect is not only entailed by the qualities of persons; taking something seriously is a preparedness to act in relation to it. To properly care respect others (and oneself) is to adopt a demanding, self-reflective approach, sincerely attempting to see the world through another's eyes. Thus, religious beliefs ought to be recognised as a constituent part of the individual person and their worldview should be acknowledged as driving deep commitments for that person even where we disagree or believe them mistaken. Nevertheless, sometimes commitment to care respect means overriding a patient's wishes; all people deserve care respect, and respect does not entail that anything goes.

### 9.4 Autonomy and beneficence are related to CR

Respect for autonomy (RfA) is a frequently used principle in matters of religious belief and healthcare conflict, where the holding of unusual beliefs and values, be they religious or otherwise, is accepted provided the individual has decision making capacity. Beauchamp and Childress (2012) have a relatively undemanding approach, and the law considers that unwise or bizarre beliefs do not themselves indicate incapacity. Nevertheless, some authors such as Savulescu and Momeyer (1997) demand a level of reflectiveness that is simply unreasonable for the majority of people (e.g. Feinberg 1989, McClean 2009). RfA which is based on an idealised conception of rational agency is exclusionary of the many people who lack formal training in 'thinking'. Under CR there is no requirement for an overly demanding approach which is too limiting and restrictive of particularity; someone who is a trained rationalist is no more or less a person to whom we owe recognition respect than a flat earther is. Nevertheless, it remains important that the patient is able to understand something of the reality of their medical situation in terms of the fact they are ill and the likely effects on their life of the disease and treatment. CR also requires protecting the vulnerable, and it

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would not be care respecting to leave those genuinely unable to decide for themselves without care and support.

Inauthentic, incoherent or non-voluntary religious requests are often exempted from accommodation due to the importance placed on conventional reading of liberty and autonomy (e.g. Hyun 2001, Beauchamp, Childress 2012, Hyslop 2017). However, it is important to realise that no-one is fully authentic, fully coherent, or fully independent of others (e.g. Feinberg 1989, Baier 1985, Code 1987b). In order to determine how the patient themselves experiences their religious expression, and from proposed accommodations, it is therefore acceptable and necessary under CR to engage with, and examine, a patient's religious beliefs.

Nor, under a CR approach to autonomy, ought requests based on religious beliefs by persons other than the patient be considered ethically binding because to do so is to impose one's own beliefs on others in a way CR does not support.

Providing for the needs of others by caring about their flourishing and wellbeing, a requirement of CR, exceeds the limited positive obligations imposed by RfA. The duty of beneficence that exists within healthcare (e.g. Beauchamp, Childress 2012, Hoyt-O'Connor 1999, Pellegrino, Thomasma 1988) falls short of the benevolence which care respect requires. Additionally, although the demands of care are extensive, we need to exercise caution before assuming that caring is, or should be, the domain of women (Held 2006).

Neither care respect, nor beneficence, ought to be restricted only to the biomedical issues. To be respected as a person and to be a healthy person requires attention to the harms which occur from non-physical forms of suffering. Where accommodating religious beliefs promotes wellbeing, even if this sometimes involves biomedical harms, then it is in keeping with CR. Evidence demonstrates that accommodating religious beliefs does indeed improve

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wellbeing across a variety of specialisms and likewise, that ignoring religious/ spiritual concerns can be actively harmful. When religious or spiritual belief is supportive of the patient's well-being, broadly considered, CR and beneficence require accommodation.

# 9.5 CR supports limits on the extent of accommodating religious beliefs in health care

Under CR, a patient may refuse care, and the scope of others to impose is limited. Also, CR's particular approach requires some facility to provide, at least a minimal respect, to the religious, and religious type beliefs of all patients. However, some religious beliefs and/or accommodations might bring harm to others besides the patient, which would be contrary to the need to care respect those who were so harmed. CR is owed, as a basic recognition respect of the needs of persons, to all.

We are justified in limiting accommodation even if we seek to be tolerant of other's beliefs (e.g. Fiala 2005, Engelen, Nys 2008, Forst 2004). Commitment to basic respect to all persons forms the basis of tolerance under CR, and it also imposes the limit; we would not need to tolerate, or accommodate, beliefs that are not at least minimally care respecting of others.

Another limit is imposed by harm (e.g. Mill 1869, Feinberg 1989, 1988, Beauchamp, Childress 2012). The scale of those harms and the ability of the perpetrator to recognise them as harms would modify our responses to the harmful behaviours, as CR entails respecting people as they are. Nevertheless, under CR beliefs that harm others need not be accommodated. This includes the harms caused by loss of dignity, by ignorance of the importance of a patient's belief, and by disrespect towards patients who hold beliefs. Although such attitudes towards patients are against the requirements of professional ethics; pervasive falsehoods, media portrayals of religion, and a scientific approach to medicine contribute to the low weight

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religious beliefs might be given (e.g. Butler-Sloss 2015). An organization such as the NHS, that promotes a non-judgemental, non-discriminatory environment (NHS 2015) can use CR to legitimately limit requests that are based on the dehumanisation of others.

Limits can be supported by a framework of rights and equality, which call for accommodation and recognise the legitimate interest of society in protecting its members and itself. Such frameworks are in keeping with CR, but sometimes they overlook the individualised nature of beliefs (Equality and Human Rights Commission 2017). Where individual rights might threaten the equally significant rights of others, limits are legitimately imposed, but such things should not prioritise how well a belief accords to one mandated by a religion, but to how important it is to the individual concerned.

CR also requires, that in giving CR to all, there is recognition of the necessary constraints of possibility and limited resources. There cannot be an ethical obligation, given the reality of the environment, to provide what simply does not exist (Stern 2004). However, below the level of impossible there is a need to establish whether a particular request is actually impossible, or just *difficult* to meet. Something like the continued provision of chaplaincy services, or the availability of clearly labelled and treatments are necessary to properly meeting the needs of patients. There are also occasions on which accommodation may not be morally required, but it may be morally permissible- such as the use of expensive but futile technology in some circumstances (Orr, Genesen 1997), this is not the case if providing it seriously limits the care that can be given to others. For example, it is legitimate to prioritise someone who will recover if given access to an intensive intervention over someone who will not where it is impossible to do both.

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### 9.6 CR's requirements

In light of the above, CR requires:

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- Taking seriously the beliefs and worldviews of a concrete individual because their identity is substantially derived from their fundamental, life reconciling beliefs, (sections 2.1, 4.1, 4.6)
- 7330 2. Taking seriously the importance of those beliefs in terms of their being moral obligations (section 4.5), and
  - 3. Taking seriously the individual as a *feeling being* capable of experiencing suffering and wanting a particular type of life for themselves (section 4.2).
  - 4. The patient recognizes that the nature and consequences of the condition apply to them in general terms (section 5.4)
  - 5. The beliefs the patient holds are genuinely held by them (section 5.3, 5.4)
  - 6. Accommodating the belief affords a benefit to the person requesting the accommodation *on their own terms* (section 4.9).
  - 7. The accommodation does not harm others in a way not in keeping with care respecting them (section 6.3),
  - 8. The accommodation is achievable within the restrictions of limited resources (section 6.5).

## 9.7 Existing weighting systems for accommodation are inadequate

Although CR is a good ethical concept to use when evaluating if an accommodation ought to be made, it is too broad to be action guiding in any particular scenario. Thus, further 340

application is required to use it in practice. Buryska's (2001) and Bock's (2008) multi-factored methodologies provided a possible framework for applying ethical principles to particular cases of religiously-based accommodation requests. In a new critique of these frameworks, I showed that both authors place too much reliance on the importance of 'traditional' belief 'communities' in formulating their methods.

In a CR approach, the nature of the belief and the role it plays in shaping the identity and moral conceptions of the particular individual is independent of the numbers of adherents and the historical traditionality of the belief. Bock places too much reliance on the ability of (traditional) communities to exclude harmful beliefs; the new, often highly individualised and 'odd' nature of Pagan beliefs would not be as well accommodated as the more familiar Christianity. Assumptions that Pagan beliefs are weird or bad already contribute to Pagans' negative experiences. Buryska places much less emphasis on the *nature* of a community; he gives all communities a central role regardless of whether they are harmful and conceives of accommodation as a matter of negative rights, rather than positive ones. Bock's criteria therefore potentially exclude Pagans, and Buryska's criteria may allow deeply harmful beliefs to be accommodated and neglect the importance of obligations to 'care about'. For many Pagans, particularly eclectic Pagans, identifying a community is difficult, particularly as the dogmatic institutions of 'Western' religions are the very antithesis of their beliefs (Davy 2007, Harvey 2011).

Nevertheless, some elements of the proposed systems, do reflect justified limitations on accommodation, and the overall approach is useful in enabling any particular 'belief and request' accommodations to be evaluated ethically. Bock's no-harm condition reflects the harm limitations imposed by CR. Buryska's account (criticisms of the concept of impartiality

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notwithstanding) identifies that concerns of justice can legitimately add weight against a particular incidence of accommodation.

Notably absent, though, are criteria that *expressly* consider the actual benefit to the believer, and criteria that recognise the frequently 'obligation imposing' nature of this kind of belief. Both of these are deeply important to CR.

## 9.8 A CR approach can be used to shape a framework for accommodation

Creating a practical tool to foster a CR approach to accommodating religious beliefs in healthcare requires using the requirements of CR and the structure of a weighting methodology. Such a method gives weight to the claim for accommodation if certain criteria are met and reduces the weight if they are not. Should a request meet all five criteria in the CR approach, it ought definitely to be accommodated. Should it meet only one, then it most likely ought not.

It is important that fulfilling the criteria in any individual case is not prohibitively demanding for ordinary people. People deserve respect because of their nature as particular humans with their particular beliefs, not as ideally rational thinkers. Under CR, there is nevertheless a requirement made on a cognitive capacity basis. The patient must generally understand their medical circumstances. This need not be detailed or nuanced, but the patient must be aware of their condition and the likely trajectory if they accept or refuse the offered treatment. The values they chose to prioritise in making their decisions are theirs to use as they find appropriate. Because such values ought to stem from the patient, attention ought to be given to the voluntariness of the belief and accommodation request.

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The criteria require express consideration of the nature of the belief. This is because of the identity giving nature of a religious world view. Additional support in identifying the kind of belief that we see as important to the person, comes from the way in which the request for accommodation reflects a moral obligation or duty the belief imposes on the patient. Should someone hold a belief frivolously, completely incoherently or under autonomy limiting pressure from another, these criteria would most likely not be met.

The request must also give a benefit to the patient. Often, benefits are considered as being restricted to biomedical ones, but they ought to be considered more widely; identity, integrity, promise-keeping and spiritual contentment are all important parts of the person. However, CR is attentive to particularity; what one person finds valuable and relevant will differ from what another person finds so.

Some religious beliefs are recognised as not being helpful to the patient, such as those where they perceive themselves as being punished or as a bad or undeserving person. Such beliefs may fail to meet this criterion, but those involved in a patient's care must also take steps to see if the patient is in some way gaining a sense of integrity or strength from adopting such a burden. It is also important to remember that all people benefit when they are treated respectfully and with understanding in healthcare scenarios, rather than disdainfully or ignorantly. Previous weighting systems have not made the benefit to the patient explicit, so proper attempts to discover what the patient gains from their request may not have been fully explored. Also, this criterion gives weight to everyday requests for such things as alternative medications and particular diets. Given CR requires caring about others' wellbeing, it is appropriate that this criterion is included.

The recognition that CR ought to be extended to all provides good reason to prevent harms coming to those who have not chosen a particular harm for themselves, including the harms

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that come of being dehumanised. We cannot generally accommodate that which is harmful to others because under CR we have no business imposing on their interests in not being harmed. The no-harm criterion builds on the medical value of non-maleficence, recognising that sometimes a request would lead to an unwarranted harm being inflicted on a person who may not share the patient's values. The criterion also helps counter requests for accommodation that devalue certain categories of people (e.g. BAME persons, homosexuals and bisexuals, transgender folk), as such devaluing is harmful and goes against the underlying principle of care respect.

There are scales of harms in which the consequences of a simple dislike of a particular type of belief or person is less significant than, for example, depriving them of effective, life-saving treatment. Thus, we might sometimes attempt to accommodate beliefs that stipulate the gender or ethnicity of the HCP because of CR's consideration of how much such views are part of a worldview that has never been challenged. However, accommodating such attitudes is not a requirement in an emergency scenario, and nor should patients (or their families) be free to abuse staff (or other patients).

Impossible things cannot be an ethical requirement; however, serious attempts should be made to explore the possibility of accommodation. Habit and custom can make things look impossible, when, in reality, an accommodation could be made and there are strong grounds to do so. This criterion functions as a reminder that accommodation is not infinite, but that we nevertheless ought to be genuinely exploring options.

The CR accommodation tool (section 8.1), then, consists of five criteria:

- 1a) The belief is of the reconciling type and
- 1b) is actually held deeply by the patient and

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- 7440 ic) creates a moral obligation for the patient
  - 2) There is a recognisable benefit to the patient that is not restricted to the biomedical sphere
  - 3)The belief is about the patient themselves, and does not call for others to be harmed
  - 4)The patient accepts the consequences of their action and the medical situation giving rise to it
  - 5) It is possible to accommodate the belief.

## 9.9 Care Respect and the five criteria, application to the Pagan cases.

#### 7450 9.9.1 The Druid

Paul's request for an observer to be present should, *ceteris paribus*, be granted. Paul's beliefs are of the qualifying type, the decision arises out of a coherent world view that is reflected by other choices he makes in his life. He understands the medical situation and is not imposing an un-consented to harm on anyone else. Although it may be difficult to get the whole team behind the accommodation, it is possible, and clearly doing so will give Paul the best medical chance possible whilst reducing his demands on other areas of the service. It may also be possible that involvement of others who share Paul's beliefs and an understanding of the medical requirements and difficulties could negotiate an alternative, but with Paul refusing dialysis there is a narrow time window.

#### 7460 9.9.2 The Wiccan

Katy's request for non-animal derived sources should absolutely be accommodated, including clear disclosure of the ingredients of treatments and honesty where the ingredients are not known. There are additional costs involved, but these are not prohibitive. However, as surgeons cannot realistically choose to badly perform a surgery, this accommodation cannot be made, necessitating a choice of surgery vs no surgery. Her belief that she is being punished is something that would benefit from the involvement of others of the same beliefs, because it is difficult (but not impossible) to see how it fulfils the criteria of being good for the patient.

Because of the obligation to recognise where a patient is in their particularity, the staff ought to consider how the patient is reacting to trauma and if it genuinely is affecting her thinking. This encourages the staff to take time to discuss the situation with the patient and get to understand her reasons and motivations, and to clarify any important facts. It is, for example, relevant to point out that even the best treatment will leave noticeable scars, because this seems to be particularly relevant to the patient.

#### 9.9.3 The Heathen

Simon's request could be given priority, although it is by a very slight margin. Although Simon's request, like Karen's, is based on something most people do not understand, it fulfils the elements of the reconciling view and of an obligation – honouring a religious promise – that is not present in Karen's case. Meeting the religious obligations of his beliefs is more integrated into his understanding of the world than is Karen's desire to attend a conference. That said, in the scenario, both patients were treated dismissively in a way that was not indicative of care respect. The events were clearly deeply important to both patients, and

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although Simon has a slightly greater claim on the slot because of the nature of his beliefs, this should not equate to Karen being abandoned to walk out, given there are pressing issues of patient wellbeing at stake. For example, if Karen is concerned about losing money, staff could provide evidence for the conference organisers to see if the money can be refunded. Clear details of how to attend for ambulant day case on the day after the conference could be offered, to minimise Karen's wait if she does decide to leave. Care respect requires that both patients are entitled to kindness and understanding regardless of how unusual their motivations.

### 9.10 Investment in staff training is required by CR

A weighting tool would need to be supplemented with other practical measures in order to be effective, which themselves would also improve care for patients with religious beliefs. Care respect calls for staff to be able to understand the particular patient in depth, and so does professional guidance, but in practice studies indicate that many professionals feel unable to engage with patients about spiritual issues or were inadequately aware of the issues (e.g. Koenig, Bearon et al. 1989, Ellis, Narayanasamy 2009, Moynihan 2008, Culatto, Summerton 2015, Morgan, A. 2017). Research and experience suggest that religious and spiritual care is not perceived as being adequately covered in medical and nursing education, and this may be seen in the awkwardness of care providers around this issue.

Health care professionals need to be aware of the diversity and importance of religious beliefs, particularly of those outside their own tradition or of those who make up a substantial portion of the population where the practitioner works. Practitioners should be taught how to take an interest in a patient's religious belief without pressing their own (or lack of). Particular care should be taken to reduce the negative views of particular religions

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and beliefs which can subconsciously influence care. Thus, further training that helps HCPs understand religious and spiritual perspectives leads to greater ability to care for diverse patients.

To do so would not be easy and would require time and money to be spent on the curricula of health professionals, against which other concerns would need to be balanced. However, the aim of this professional education is not to produce health professionals with an encyclopaedic knowledge of comparative religion. Instead, it is aimed at developing HCPs with cognitive empathy (Hojat, Gonnella et al. 2003), who can recognise important elements of religions, spirituality and worldviews they may encounter and work with the patient in a care respecting way.

Spiritual history taking tools exist to establish the importance of, and effect of, the patient's religion (and other values) in their life (e.g. Koenig 2008, 2004) and ought to be routine. A simplistic registering of the faith group to which a patient belongs is not adequate to properly accommodate religious beliefs, proper monitoring of the religious patient experience is required, but some trusts do not seem to collect this data at all (Clayton 2010). Adopting spiritual histories as routine and evaluating how satisfied patients are regarding their religious needs being met, would both contribute to improving patient experience.

Some authors (Bock 2008, Orr, Genesen 1997) recommend the role of 'religious interpreter'. Given many patients are not comfortable and experienced at articulating their reasoning, and that many HCPs are not familiar with a particular patient's worldview, the RI acts as a translator between the patient and the staff. Chaplains, HCPs of the same faith, and the patient's family often adopt this kind of role in practice. Although neither paper suggests an RI ought to be a paid position, in an increasingly secular society, such a non-denominational role might be a means to facilitate the meeting of patients' religious and spiritual needs.

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Broadly, the RI is someone who has training and experience in understanding people's religious needs, whilst also being medically literate. They would be distinct from most chaplains in that they do not have an explicitly religious or celebrant role, but rather they solely help mediate between the patient and the healthcare staff. This includes ensuring that the patient's religious and spiritual needs are genuine and met, that the medical situation is explained to the patient in appropriate terms, and that the nature of the patient's belief is articulated to the medical staff.

Funding and accepting an entirely new form of health professional would require considerable investment, and the research to support such a move is not in place. However, it could also be a specialism for some HCPs which might alleviate some of the concerns. In recognising what an informal RI does, attention can be paid to the barriers which prevent patients with religious beliefs being adequately care respected.

### 9.11 Further work

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More empirical work is needed to explore the experiences of Pagans in healthcare. There are a few articles which refer to Pagan needs and experiences, but little in the way of a wholesale understanding of how Pagans particularly experience medical provision in the UK. This work would increase understanding how Paganism impacts on patients, staff and their care. A similar study that explored Pagan's attitudes towards ethics in healthcare – indeed whether there was a distinctive Pagan medical ethics- would be informative for both healthcare and Pagan studies.

Pagan members of staff may also hold beliefs about the unacceptability of abortion and or types of end of life care. More ethical work is required to look at how ideas about these beliefs intersect within medical professionals, for whom medical values may also be identity

conferring. There are remaining questions about the extent to which the duties of a medical professional ought to be expected to limit expression of other values.

Care respect, in this thesis, has been suggested as a way of responding ethically to those with religious beliefs in healthcare, by adopting a particular attitude of respectfully caring about people in their particularity. Although it seems to perform this function well, the effectiveness of the resulting CR based tool would need to be demonstrated in practice.

I did not fully critique CR itself, instead adopting it as a response to other concerns about the nature of persons and respect. Thus, CR could be further evaluated and developed in and of itself. When it was first discussed, it was considered to be a good development of the need to fuse care ethics and respect for others, but little has been done with it since. I find this unfortunate, because it is an accessible, if demanding, normative approach which has elements of respect for autonomy, care, equality and virtue. The way in which CR relates to concerns of Justice are only hinted at in Dillon's work, and therefore, more discussion of how CR either dictates or sits alongside existing frameworks is also warranted and necessary. Further application of CR to the treatment of other groups of people is possible and ought to be considered. For example, LGBTQIA folk, elder patients, or patients with severely limited autonomy, also have particular experiences with healthcare which might benefit from a CR approach.

#### 9.12 Final comments

When I was a Pagan in hospital, I felt dehumanised and disrespected when my beliefs were marginalised. Something very core to me was dismissed as an irrelevance. I deeply appreciated that the department was understaffed and busy, that my finances did not dictate my care, and that the primary motivation of the NHS was to restore biomedical functioning.

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Nevertheless, it *hurt* to be dismissed. Kindness, care, compassion and respect are considered to be key parts of the NHS's healthcare role, but here they were reduced to indifference and efficiency.

The arguments about rationality and autonomy and futile treatment seemed to be very remote from this brief, everyday experience. I wanted someone to tell me they cared about what mattered to me, to be respected as a particular person. I had a good education, some training in medical ethics and connections to healthcare practice. I saw the other principles in operation, and yet I still felt ignored. Those without those advantages might suffer more indignities and ignorance rather than be branded difficult.

With financial pressure and a growing population, it seems easy to lose simple human kindness and 'caring about' in the rush to do as much as possible with less. Yet, caring about, as opposed to simply caring for, really *matters* if we are to be serious about respecting persons. Care respect, in bringing together respect for another's ends with an understanding of the complex relationships of care ethics, offers a way of framing our moral seriousness. Human lives are not lived by abstract principles; rational capacity and biomedical need are important but only part of the story of treating humans well. The relationships we have with others, our need for caring interactions and our sense of who we are as a unique individual are also critical. If an ethical approach devalues these, then just what and who is it for?

The demands of ethics apply as much to the staff with the grumpy Pagan patient on ward three as it does to the surgeon whose patient is a Jehovah's Witness refusing a transfusion. The reach of healthcare is wide; there will need to be more discussions around how identity conferring beliefs are accommodated in social care, in care homes, in the community, as much as hospitals. Healthcare ethics needs to address the matters of everyday respect as much as it would address a life and death dilemma.

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By placing and keeping caring about and respecting persons at the centre of the ethical discussion, care respect has the potential to inform both the major and the everyday requests for accommodation of religious (and other) belief. Care respect is demanding, but if we are to be serious about our obligations to others in healthcare, I see it also as profoundly necessary.

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