

Older Lesbians, Gay Men and the ‘Right to Die’ debate: ‘I always keep a lethal dose of something, because I don’t want to become an elderly isolated person’.

Abstract

This article considers the ‘right to die’ debate from the perspectives of older lesbians and gay men, drawing upon data gathered for a PhD in Law. My argument is that older lesbians and gay men are multiply disadvantaged: a) by an increased risk of feeling that life is not worth living due to affective inequalities (inadequate informal and formal social support) and b) by a denial of access to the ‘right to die’ both under such circumstances and/or if they wish to resist the normativities associated with a passive, medicalised death. I argue for the need to distinguish between a wish to die because of deficiencies in the care system and a wish to die in order to control how, when and where one’s life ends. My analysis highlights the contextual contingencies of ‘vulnerability’ in relation to the ‘right to die’ and interrogates the heterosexual and disciplinary reproductive normativities underpinning notions of ‘natural’ deaths.

Key words: older lesbians and gay men; ‘right to die’; vulnerability; inequality; assisted dying; euthanasia.

INTRODUCTION

The ‘right to die’ is the subject of considerable legal, ethical, clinical and political debate (Yeung 2010). With an ageing population, and more people living longer, but not necessarily with a good quality of life in their final years, the debate has expanded to include its implications for older people, particularly those with dementia (Tomlinson and Stott, 2015). Yet older⁽¹⁾ people’s voices are rarely heard in the debate (Lamers and Williams, 2015), especially those of older lesbians and gay men. This article addresses this knowledge gap, by analysing the narratives of twelve older lesbians and gay men who support the ‘right to die’, many of whom have plans to end their lives⁽²⁾, taken from a wider dataset from a PhD Law project (Westwood 2015a).

My argument is that older lesbians and gay men are multiply disadvantaged: by an increased risk of feeling that life is not worth living due to affective inequalities (inadequate informal and formal social support); by a denial of access to the right to die both under such circumstances; and/or by a denial of access to the right to die if they wish to resist the

normativities associated with a passive, medicalised death. I argue for the need to distinguish between a wish to die because of deficiencies in the care system and a wish to die in order to control how, when and where one’s life ends. My analysis highlights the contextual contingencies of ‘vulnerability’ in relation to the ‘right to die’ and interrogates the heterosexist and disciplinary reproductive normativities underpinning notions of ‘natural’ deaths.

In the first section I locate older lesbians and gay men in the ‘right to die’ debate. After a Methodology section, I then describe and analyse the findings, before discussing their implications, for older lesbians and gay men, older people in general, and the new insights they offer to the wider ‘right to die’ debate.

OLDER LESBIANS, GAY MEN, AND THE ‘RIGHT TO DIE’ DEBATE

The ‘right to die’ debate (Yeung 2010) is not just about the right to die, it is also about the right to be assisted, either indirectly or directly, in doing so (Ost 2010). Assisted dying refers to providing physical assistance to someone who wishes to end their life (e.g. obtaining the pills, lifting the cup to the mouth, etc.). Euthanasia refers to ending someone’s life for them (e.g. administering a lethal injection). In a systematic review of the literature on patients’, carers’ and public attitudes towards assisted dying, Hendry et al (2012, p. 17) identified four main themes:

- Concerns about poor quality of life: *unbearable suffering, dependency, burden and loss of self, physical pain and suffering and fear of future suffering*;
- The desire for a good quality of death: *autonomy and control and the right time to die*;
- Concerns about abuse if assisted dying were legalised: *the need for safeguards, financial pressure, vulnerable groups and discrimination and the role of others in decision-making*;
- The importance of individual stance related to assisted dying: *moral or religious views, personal experience of death or suffering, being for or against the availability or legalisation of assisted dying*.

Lamers and Williams (2015) in a Foucauldian analysis of older people’s discourses about euthanasia and assisted dying (their sample demographic was not analysed for sexuality/ sexual

identity), identified two further themes: dying inside and outside of ‘the medical gaze’ (p. 1); and notions of a ‘natural cycle’ (p.7) of birth and death, with dying in older age preceded by physical and mental decline.

The ‘right to die’ debate is intertwined with moral values (Cooley 2013; Prado, 2013), ethical dilemmas for healthcare professionals who might be required to perform the assistance to die/euthanasia (Biggs and Ost 2010; Huxtable & Mullock 2015) and ‘dichotomised positions’ (Mishara and Weisstub, 2013, p. 427) between narratives of resistance and empowerment (‘the triumph of autonomy’, Beauchamp, 2006, p. 646) and contrasting tragedy narratives (‘so sad and desperate’, Andrews 2015, p105). The debate is not only abstract and theoretical, but has real implications for lived experience, as evidenced in the growing body of case law (Bara and Vyshka, 2014; Tiensuu, 2015) where people with chronic, terminal conditions, have unsuccessfully petitioned for the right to be assisted in dying, including *Pretty v United Kingdom* Application No 2346/02, Merits, 29 July 2002; *Bush v. Schiavo*, 125 S. Ct. 1086 (2005); *Haas v Switzerland* Application No 31322/07, Merits and Just Satisfaction, 20 June 2011; *R (Nicklinson) v Ministry of Justice* [2013] EWCA Civ 961. Notably, and by contrast, in Canada this year following *Carter v. Canada* (Attorney General), 2015 SCC 5, Canadian adults who are mentally competent and suffering ‘intolerably and enduringly’ now have the right to receive medical help to die (to be enacted in 2016). However, in many countries, including the UK, assisted dying is still against the law.

Feminists have had long-standing involvement in the ‘right to die’ debate (Wolf 1996), expressing concerns that the unwanted and/or unsupported in society might be encouraged to end their lives rather than the state addressing the systemic reasons for their social exclusions and/or lack of support (Tulloch 2005). They have also emphasized the ‘slippery slope’ argument: ‘if voluntary euthanasia is legalised it will become impossible to make a distinction between voluntary euthanasia and non-voluntary or even involuntary euthanasia’ (Ost and

Westwood, S., 2017. Older Lesbians, Gay Men and the “Right to Die” Debate. *Social & Legal Studies*, p.096466391769391. Available at: <http://dx.doi.org/10.1177/0964663917693916>.

Mullock 2011, p. 183-4). Many feminists are concerned that ‘vulnerable people will be disproportionately at risk – that under the banner of “choice”, women, the elderly and the disabled will be targeted for assisted dying (or feel pressured into ‘volunteering’ themselves)’ (Kitzinger 2015, p 102). Some feminist care ethicists take a particular stance: ‘feminist values of equality, inclusive justice, caretaking, relationship, and the interconnectedness of life impel us to struggle against self-determined forms of death’ (Callahan 2015, p112).

Other feminists have critiqued healthcare law, arguing that while narratives of (embodied) choice prevail ‘law also works to define the boundaries of permissible choices, since some requests for bodily interventions are ruled out’ (Fletcher, Fox and McCandless 2008, p. 324). The privileging of vitality and of respect for life claims (p. 329), can remove an individual’s right to exercise choice and control through ownership claims over her body. As Fletcher et al write,

Why is the fact that a person no longer values her living body not treated as sufficient reason to justify the provision of euthanasia or assisted suicide? Why does law not accommodate a woman’s judgement that it is best to end a particular pregnancy at a given moment? These familiar questions interrogate legal restrictions on bodily choices in reproductive and end of life contexts. (p. 335)

With an ageing population and the increasing prevalence of dementia, especially among women⁽³⁾, older people, especially those with dementia, have been increasingly implicated in the ‘right to die’ debate (Tomlinson and Stott, 2015) and feminists have positioned themselves on both sides (Kitzinger 2015). There are significant concerns about the quality of formal care provision for older people (EHRC, 2011; WHO 2011; Osborn et al 2014). As Jonathan Herring has recently observed,

Older people are dying in poverty, freezing temperatures, and desperate hunger. So many are neglected by their communities, abandoned by their families, living isolated, socially excluded lives. For many, their last months or, if they unlucky, years are spent in care homes marked by abuse, neglect, and over-medication. (Herring 2013, p. 496).

Feminists have long-argued that, if older people want to die because of inadequacies in care provision, then rather than according them the right to die, that provision should be improved,

If care is ineffective and humiliating we need to improve the care—because in some cases, the problem is not the condition but the poor care provision. I often hear people saying, ‘I’d rather die than go in a care home’. But indignity in a care home is not inevitable. Care providers just need to sharpen up. (Andrews 2015, p105)

There are numerous constraints on getting care providers for older people to ‘sharpen up’ as Andrews puts it, not least of which are economic ones, as well as the cultural devaluation of (embodied) care (Twigg 1999). Opposing the ‘right to die’ for older people without improving their living circumstances can deny them an exit,

Are those supporting a right to die not concerned at the misery facing so many of our older people which will lead them to request death? Are those opposing a right to die aware of what we are otherwise leaving older people to face? (Herring 2013: 498)

Older lesbians and gay men are more likely to require formal social support sooner than, and in disproportionate numbers to, their heterosexual peers, due to a comparative lack of intergenerational informal social support (Westwood 2016a). This means that they are also more likely to be affected by the shortcomings of older age care provision, especially older lesbians (Westwood 2015b), primarily because women live longer than men and are more likely to have dementia. Moreover, older age care provision is perceived as being particularly unable to understand, recognise and/or meet the needs of older lesbians and gay men because of heteronormativity, heterosexism and homophobia (Guasp 2011; Ward, Pugh and Price, 2011; Willis et al 2014; Neville et al, 2015; Westwood 2015c and 2016c; Westwood et al 2015). This means that older lesbians and gay men are multiply disadvantaged in relation to the affective equalities of ‘love, care and solidarity’ (Lynch, Baker and Lyons, 2010: 3) – both informal and formal - and access to safe homes and living environments in older age (Barnes 2012).

There is very limited research on older lesbians and gay men who plan to take their lives (Haas et al 2011) and no data as yet relating to those who have actually done so (Blevins and Werth, 2006). This is partly because death by ‘suicide’ (at any age) is not recorded by

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sexuality/sexual identity. However, older lesbians and gay men are at increased risk of factors associated with ending one’s life: loneliness, isolation, depression and poor social support (National Institute for Mental Health in England, 2009; Fredriksen-Goldsen et al 2013).

The wish to die is not always about illness, suffering and depression. Tierney (2010) has distinguished between those in favour of the ‘right to die’ in the face of unavoidable suffering (while still accepting juridico-medical authority) and the more radical argument put forward by Foucault, which rejects the social construction of the (passive, compliant) subject in the juridico-medical model. Foucault articulated a ‘right to suicide’ (Golder, 2011, p295), arguing that ending one’s life is the ultimate resistance to ‘the calculated management of life’ (Foucault 1979, 140) through state administration of medical and social welfare systems i.e. ‘bio-power’ (Foucault 1979: 140). Several authors, building on this approach, have argued that the medicalization of dying and death (Coggon 2010; Ost 2010), ‘the institutional governance of timely deaths’ (Broom 2005: 226) and ‘a compulsory ontology of pathology in professional accounts of suicide’ (Marsh 2010: 28) all serve to produce disciplined dying subjects whose resistance, by ending their own lives, is the ultimate expression of autonomy (Beauchamp 2006).

There is a risk that a wish to have the right to die for reasons of choice and resistance can be obscured by protectionist concerns about vulnerability. Margrit Shildrick has argued that people with disabilities might be unfairly disadvantaged on both sides of the ‘right to die’ debate; on the one hand ‘the fear of disabled people is that they are excluded from the categories of lives that matter’ (Shildrick, 2015, p156) and so may be more vulnerable to unwanted euthanasia; on the other hand, that disabled people can be denied exercising the right to die (by ending their lives themselves) in ways which other people without severe disabilities are able to do. There are similar arguments in relation to older people: that they may be vulnerable to being coerced/forced into unwanted deaths; and yet may also be denied the ability to end their

own lives if they want to because of physical and /or cognitive incapacity and because of issues of consent, which do not affect more able-bodied and minded adults.

The themes of vulnerability and resistance, and uneven social contexts which predispose people to wanting to die, run through the ‘right to die’ debate. As will be seen in the data analysis, the narratives of the twelve lesbians and gay men both engage with, and offer a range of new insights on, these issues and their inter-connectedness.

METHODOLOGY

The data subset analysed here is drawn from a wider dataset comprising the empirical component of my PhD thesis, which interrogated how the intersection of ageing, gender and sexuality impact later life equality (Westwood 2015a). The project was given ethical approval by Keel University’s Ethics Committee. Ethical issues (researching hidden populations; insider/outsider dynamics; and anonymity in sensitive research) were addressed in the Methodological section of the thesis (pp 107-116) and were also explored in a paper published in a peer-reviewed journal (Westwood 2013). Semi-structured interviews were conducted with sixty older LGB individuals. Participants were recruited via online advertising, networking, opportunistic and snowball sampling. Data were analysed using a staged process of thematic analysis (Braun and Clarke 2006). In total, sixty interviews were conducted. Of these, twelve participants engaged with issues relating to the ‘right to die’. All twelve of these participants’ narratives are analysed here.

Interviews were audio recorded and then transcripts prepared for analysis. These were sent to participants for verification and/or corrections. The final version, approved by each participant, was then used for analysis. Thematic analysis (Guest, MacQueen and Namey, 2012) is one of a number of subtly different ways qualitative researchers identify, analyse, and report patterns within data (Creswell, 2007). This approach was chosen in order to make an interpretive analysis (Boyatzis, 1998) without then generalising it into an overarching new

theory, as in grounded theory, for example. The staged approach to thematic analysis, as described by Braun and Clarke (2006), was deployed. Themes were identified in a number of ways: for the frequency of their presence; for the significance placed upon them by (some) participants; for the ways in which they complicated one another; and for their saliency and significance (Buetow, 2010).

Participants were asked a range of questions according to a semi-structured interview schedule. Choosing to end one’s life was *not* one of the research questions and was not something the interviewer had intended on focussing on during the interviews. The subject came up, however, when participants were discussing their preferences for care and support in later life (which was one of the research questions). This resulted in a number of participants saying that they would not/ hoped they would not need to make those choices because they intended to end their lives and/or hoped they would be ended for them. These unsolicited responses paint only a partial picture of all the participants’ perspectives. It is not possible to say how the other participants’ viewed end of life issues, because this was not part of the research remit and all participants’ views on this topic were not routinely sought. This paper therefore is not intended to suggest these particular viewpoints are representative of the whole sample, or indeed of older LGB in general. Indeed, obtaining a representative sample with LGB individuals is extremely difficult, because it involves accessing hidden, marginalised populations of uncertain constituencies.

The participants’ narratives about formal care provision relate to anticipated future care, not care they are actually receiving. A criticism of an anticipatory narrative approach to care (Pugh, 2012) is that it is not a reflection of actual care that is/will be experienced. However, as this study demonstrates, anticipatory research is not always about mere ‘imaginings’. Many of the participants’ were supporting or had supported friends, lovers, partners and extended family

in receipt of older age care provision. These individuals’ projections about their own care futures, were thus grounded in their witnessing of older age care provision (Price 2012).

All but one of the participants this study identified as white British, and the majority were well-educated and relatively affluent, reflecting the standard profile of LGB samples (Grossman, 2008). For a profile of all 60 participants, please see Table 1.

<INSERT TABLE 1 HERE>

For a profile of the 12 participants whose narratives are explored here, please see Table 2.

<INSERT TABLE 2 HERE>

Of the nine women whose narratives are explored here, eight identified as lesbian and one identified as gay. Half (n=6) of the participants in the data subset were single, and half (n=6) were in couples. This compares with 42% (n=25) singles and 57% (n=34) in couples⁽⁴⁾ in the whole sample, so a slightly greater proportion of singles, although with the sample size not one which could be argued to be statistically significant. Only two of the women had children, and none of the men had children. This is different from the full sample, where almost half of the women and over a quarter of the men have children. This may be a significant factor, as will be explored in the subsequent analysis.

FINDINGS

ELECTIVE DYING

Participants referred to elective dying, i.e. ‘ending my life at the time and way of my own choosing’ (Stella, aged 66) in three ways: in articulating plans to end their own lives (explicit or implied); in advocating support for assisted dying and/or euthanasia; in a combination of both. In terms of the how’ of elective dying, several participants referred to overdosing, e.g.

‘the half a pint of Jamieson’s and forty Paracetamol route’ (Daphne, aged 60). They had thought their options through very carefully:

My friends do know how I feel about ending my life. I’m not joking. I’ve talked it over with them, the best way to do it. And I think I’ve decided ... The one I think I may go for at the moment... is the old exhaust pipe thing through the window. I think of all the options that’s the best. Because I couldn’t drown myself - I hate water. I couldn’t cut my wrists because I hate blood. I don’t think I’d take pills and alcohol because I’m frightened of not taking enough and I’d end up in a worse state than I already am. Shooting myself is not an option really. Chucking myself off a building. I don’t like heights, so I don’t fancy that either. So, I think, for me, it would be the exhaust pipe, drifting off to sleep. I mean the other alternative is Dignitas, but it’s very expensive and someone’s got to take you, and someone’s got to come back... (Sally, aged 73)

Sally is describing how she has thought through the different options to end her life. She, like many others, has shared her intentions with the significant people in her life. Iris, has also shared her plans with others close to her:

My visualisation, and don’t be too shocked by this, my visualisation goes as far as a particularly sheer cliff in [country] where, as I say to my partner, if I remember to go through the right departure gate at the airport and head for [country] and if I can then get across to this unpronounceable place, and jump off the cliff with my bricks in my pocket, that’s what I have in mind. For some people this might seem shocking, and it probably wouldn’t happen, but that’s how I’ve developed the idea. (Iris, aged 61).

One of the main reasons that Iris thinks she may not be able to fulfil her visualisation is that she, unlike all the other participants, has children and grandchildren:

I must say I do think about it a lot, and then I think, ‘Oh, damn, you can’t even kill yourself, because people will get upset, you know’. Grandson thinking ‘Why did she go and do that?’ and daughter thinking ‘How selfish’. So you can’t even think about killing yourself without feeling guilty. (Iris, aged 61).

Iris is describing how to wish to end her life in a particular way is constrained by her concern for how it would affect, not everyone who loves her (e.g. her partner and friends) but, specifically, her daughter and grandson. She is prioritising their feelings over hers and her (grand)parental concerns duties over her wish to determine when and how she dies.

Phil plans to use helium fed from tanks into a strong plastic bag over his head. He experienced controlled hypoxia through the use of helium during professional training:

Oh yes, [it's] a very real plan. The first symptom is euphoria. The second symptom is amnesia. The third symptom is unconsciousness. And the fourth symptom is death. And it doesn't hurt... I openly discuss that plan with anybody who is interested. (Phil, aged 62).

Phil, like Sally and Iris, has carefully explored his preferred way of ending his life and has shared his plan with others close to him, suggesting a strong element of thinking things through. Several participants expressed a wish for help in ending their lives, a number of whom had considered going to Dignitas:

[talking about a couple who had ended their lives together at Dignitas] She, one of them had dementia, or it was, you know encroaching, and one of them had physical issues and they both went together, and their children knew... and that I thought was very brave and I would hope to do that. And I've talked to my partner, about that, she knows that's my stance. (Jennifer, aged 62).

Stella also thinks she would use Dignitas. She has a very methodological approach, with a range of contingencies, the last of which, 'Plan D', would be assisted dying:

It's something I have thought about seriously. I think I would do it in an orderly fashion, because I'm a neat sort of person, so I would probably do it through some organisation or agency... You've got to have contingencies. If you can't look after yourself is one thing. But if you're living in a home and you don't like your life, and you want to try something else, you might want to have a contingency for that. And then there's the final thing, 'I'm fed up with it now'. ...So I would like to build for myself, so I could at least, when I'm really weak, I could say [*in mock hoarse voice*] 'Invoke Plan D', as opposed to Plan A, which I shall have already passed. Plan D would be the ending, that would be the pills and Dignitas. (Stella aged 66).

Stella suggested that there might be an advocacy procedure:

I think you do need other people. I mean if you'd got people who'll take exams for you, an amanuensis, someone to write things for students who couldn't write. You need someone to speak up for you, to say 'She's going to take the pill now' and you need someone, it may or may not be the same person, in the role of 'Giving the pill now'. It may or may not be encapsulated in the same person. (Stella, aged 66).

Stella is mindful of the need for safeguards to protect individuals. She also likens disability support, such as someone writing for a student who is unable to do so, with the support needed by someone who wants to end their life but cannot do so themselves. In doing so, she is framing assisted dying as an act of empowerment. The participants, including those with plans to die, expressed support for legalised assisted dying and/or euthanasia. For Rene this would only be under certain extreme circumstances.

If I was completely paralysed and dependent on other people, then I'd rather not be resuscitated. I've had sixteen operations, and I always think, as I'm going to have anaesthetic, will I wake up or will I be a vegetable, and that sort of thing. (Rene aged 63).

While Rene wishes to be allowed to die if she is completely paralysed, others saw this as a method to anyone who wants to take their own life. Stella and Phil would like their friends to be allowed to help them without it being unlawful:

I mean it's the last taboo, isn't it? I mean that would be ideal, I suppose, to have your loved ones help you at the time that suits you without them getting done over. (Stella, aged 66).

What I would like is to have a party, where there's everybody I love around, say 'OK guys, bye' [waves], stick the bag over my head, turn the valve on, please. (Phil, aged 62).

Stella is foregrounding the social and legal prohibitions over a person having loved ones with them when they end their life, which both she and Phil would like to do. While Stella and Phil wanted their friends to join them while they ended their own lives, others expressed the wish for more proactive medical intervention.

I ought to be able to say to a doctor, with a friend in the background, look, I've got Alzheimer's, or I'm paralysed or whatever, it's my life, I wish it to be over, please put me to sleep with an injection like you'd with a dog. It's so peaceful for them. It's so peaceful. (Sally, aged 73).

Sally is highlighting (as did several other participants) the double standards in the criteria for ending the life of a pet, and for ending the life of a human being. While most of the participants expressed

a wish for a means to end their lives in which they were actively engaged, May wanted a more passive elective death,

I just long for the day that they accept euthanasia. I would be scared about doing it to myself, committing suicide. But, oh for some doctor to be able to give you an injection. (May, aged 64).

May is expressing a wish to die, but a reluctance to end her life herself, and a preference for someone to do it for her. May’s wish for that person to be a doctor inevitably engages with the medical professions’ concerns about actively participating in assisting another person to die. The participants were highly critical of the current management of death and dying in older age, as will now be considered.

OBJECTIONS TO THE CURRENT STRUCTURING OF THE END OF LIFE

Participants had witnessed the care of older and/or dying people first hand, and many objected to the limited options available to people who were dying. Jennifer, had watched her friend die a long, slow and painful death from breast cancer:

And we used to talk about the possibility that she would take herself off to Dignitas... and in the end she didn’t... I wouldn’t want to die the way she did... I hope I would be brave enough to kill myself, to take control over my own death. (Jennifer, aged 62).

Jennifer, if facing inevitable death, would prefer a self-initiated one rather than a protracted passive one. She is highlighting the importance of being able to exercise control over the manner of her death while also recognising that ending one’s life is not an easy thing to do. The issue of the quality of death, raised by Jennifer, was particularly pertinent for those participants who had witnessed loved ones’ deaths in care homes:

Having seen my mother in the nursing home, and it wasn’t a bad nursing home, you know... I would rather not go... This is nothing to do with being gay or straight, but the medical advances that have been made in keeping us alive, the ethical thing hasn’t kept pace with it. You keep people alive for longer, ‘Oh we’re all living for longer’. It’s not necessarily a quality life. My mum was kept alive for god knows how many years, when all she wanted to do was shuffle off this mortal coil. It was bloody cruel. It was ridiculous. Our cat wasn’t well and so we had her put down eventually. I don’t want to be that skeleton that was lying on my mother’s bed. (Daphne aged 60)

Daphne is critically interrogating the system by which frail, ageing people are being kept alive for longer but without a meaningful quality of life, and when they actually want to die. She, like Sally, highlights the double standards for ending the life of a pet and ending the life of a human being. Phil questions the tragedy narrative of ‘suicide’ arguing that prolonging the lives of frail older people is the real tragedy,

I see people who, dodderly old condition, in hospital, being kept alive ruthlessly, and I regard that as a tragedy... for example [a friend] two years ago his dad died, it was quite plain that this man was going to die, and was in considerable pain. What is wrong with his friends and family gathering around his bed with the helium bottle, saying ‘Bye Dad’? (Phil aged 62).

Phil turns the ‘right to die’ debate on its head, arguing that it is not ending one’s life that is the tragedy, but rather prolonging the suffering of frail older people. And rather than understating the protracted care of ageing, dying bodies as compassionate protection of the vulnerable he considers doing so ‘ruthless’.

Several participants were concerned about dementia, having supported a parent and/or other family member live (and die) with dementia, and were very clear that they did not wish their lives to end in the same way,

I have an aunt who’s 84 now, I’m very close to her, she’s a bit like a second mother to me, she has dementia now, and I do the same things for and with her, that I did with my mother [who also had dementia], having a laugh and a joke with her, getting her papers together and putting her memories in front of her. But when she’s conscious enough to be aware of her feelings, she says ‘I wish I could pass on, I can’t drive, and here I am, it’s 2 in the afternoon, and I’m still in bed’. So I know up close and personal what it can be like. (Iris aged 61).

Iris has been affected by witnessing her mother and her aunt’s dementia, not only by not wanting to die in the same way, but also by seeing their distress, and her own, in the face of a wish to die that could not be put into effect. Stella also articulates how watching her aunt die made her determined not to die in the same way,

[Talking about an aunt who died in a care home] And for the last period of her life, she just sighed a lot and said ‘oh dear’. And I thought she really wants to go, but she can’t do it and I can’t do it.... (Stella aged 66).

Like Iris, Stella does not want to be in the same situation as her aunt, wanting to die, but being unable to end her own life, and there being no way another person can lawfully end it for her. She wants a pre-arranged plan whereby if she reaches the point where she wants to die but cannot end her own life, there is a system in place which allows someone else to end it. The participants expressed strong objections to not being able to end their lives in this way, as is considered next.

RESISTANCE, POWER AND CONTROL

Exercising power and control underpinned the narratives of the participants.

Well, I have actually [‘a suicide plan’]. I’d much rather I had control over that rather than live a life that was intolerable... I don’t think it’s a bad thing really. (Alice aged 60)

It’s [‘suicide’] empowering, it’s powerful. (Jennifer, aged 62).

[It’s] taking control of the way one dies. (Stan, aged 64)

I want to keep more in control if I can. (Daphne aged 60)

Jennifer frames ending one’s life as an issue of self-empowerment, while Alice, Stan and Daphne emphasize issues of control, in subtly different ways. For Alice, it is control over an intolerable life (caused by a lack of social support, see the next section); for Daphne it is about control of the ‘when’ of dying, i.e. not wanting to have a long drawn out death like her mother; for Stan it is control over how one dies. Phil links the issue of control to lesbian and gay non-conformity:

‘[We] have lived our lives with our own control of what we do...being gay has to my mind, helped me in being comfortable at looking at the world in an eccentric way. I am used to seeing the world around me as being that stupid world out there. (Phil aged 62).

For Phil, having lived a life of choosing to openly go against the heterosexist norm, is linked to him approaching dying in the same way, i.e. resisting established norms. Phil objects to the

lack of lawful means to die in the way that he wants, i.e. with friends around him, possibly assisting him in his death if needed,

My worry is, of course, the law. Because, if this is to work with the current legislation, you can't involve your friends. What I would like is to have a party, where there's everybody I love around, say 'OK guys, bye' [waves], stick the bag over my head, turn the valve on, please. But I have to do it earlier if it's me only. And that really annoys me. That's other people's wanky prejudices, really silly, dictating stupid outcomes. And that means I will die earlier (Phil, aged 62).

Phil perceives the current illegality of assisted suicide in the UK as being both normative and discriminatory ('other people's wanky prejudices') as well as irrational and unfair ('really silly, dictating stupid outcomes'). It will actually, according to Phil's perspective, result in an earlier death than he might want, because he will have to take his own life while he is sure he can still do so independently. This concern about the need for an early death because of the need to be able to end one's life without help was shared by a number of participants: 'by the time I would want to I might not be able to do it' (Stan, aged 61). This also engages with issues of resources, as is highlighted in Sally's interview:

...the other alternative is Dignitas, but it's very expensive and someone's got to take you, and someone's got to come back. I'd rather give my money to my charities. It's a lot of money to be able to do something you ought to be able to do in this country and at home (Sally aged 73).

Sally identifies here how individuals who want to go overseas to die need the economic (money) and social (people to take you) resources in order to do so. A lack of such resources constrains a person's ability to exercise resistance in this way. Ending one's life as an act of resistance was most clearly articulated by Stella,

I don't think I used the word suicide, if you'll notice. I think I talked about ending my life at the time and way of my own choosing, which I what I regard it as. Because I think the word 'suicide' has a pejorative tone and don't forget it's only since 1928, no, some other date, when it was not a crime. I think people talk about suicide and it does have a... I mean, maybe people like Terry Pratchett and people like myself will reclaim the word 'suicide' much as 'queer' has been reclaimed. But I think if you talk about

suicide to the man or the woman in the street, they have as preconceived an idea about that as they do about age (Stella aged 66).

Stella creates an association between transforming the word ‘suicide’ and transforming the word ‘queer’ from a pejorative to a term of self-/ collective- empowerment. She also expresses the perception that the denial of the right to die is discriminatory (by linking it to ageing stereotypes), echoing Phil’s reading of it as ‘other people’s wanky prejudices’. Asserting the right to die, then, is seen by those who wish to have this right, as a key site of resistance to the disciplining of death and dying, and denial of the right as a site of oppression.

INADEQUATE SOCIAL SUPPORT

For most of the participants there was an interplay between a insufficient/inadequate social support and wanting to die. Rupert, aged 68, suffered physical abuse by his father for most of his childhood (‘I suspect he made some kind of calculation that this wasn’t, really, the type of son he wanted’) and his family are not accepting of his sexuality (‘my mother said to me “I’m so glad your father didn’t live to see you living like this”’). Robert, who identifies as White British, has suffered from severe depression for much of his life and now supports his civil partner⁽⁵⁾, who is from a minority ethnic background, and who has a recurrent psychotic illness. They have few friends and live very near Rupert’s biological family – his brother, sister-in-law, niece and her husband - but they receive no support from them: ‘They don’t like gay people. They don’t like different ethnic groups. And they don’t like mental illness.’ (Rupert, aged 68). This informs Rupert’s future plans:

Well, I, to be honest, I always keep a lethal dose of something, because I don’t want to become an elderly isolated person. And I certainly don’t want to be a burden to other people. And also, it is possible my mood will deteriorate again. And it’s quite hard to deal with. And there isn’t that much support, to be honest... I’ve come to realise that when it’s my turn to need support, I’m going to be in a bit of a vacuum..... there will be a point at which, I think, it will be wise to exit. (Rupert, aged 68).

Rupert articulates a combination of factors informing his plan to end his life: loneliness and isolation; being a ‘burden’ to others; recurrent depression; and a lack of support. There is also

a cycle of inequality in his life, with early family rejection (in Robert’s view) contributing to his depression and an ongoing lack of family support compounding it. Intergenerational support was also a recurring theme.

I think the Continentals had the right idea, multi-generational [living], but I’ve done bugger all about it, I don’t have any children or grandchildren, so I’m not going to be looked after by anyone else (Jennifer, aged 62).

I don’t have kids... The psychology in the breeder world [is] you have lots of kids, so they’re your pension, so that sort of psychology stacks for a lot of heterosexuals, ... [Talks about friend who gets a lot of informal support from his four children] I have younger people in my world, but I don’t think they would do that for me. (Phil, aged 62).

Both Jennifer and Phil identify the importance of children and young people for intergenerational support and their sense of a ‘deficit’ in this regard. However, having intergenerational relationships is no guarantee of support. Tessa is talking here about who would support her in old age if her civil partner, Ellen, died,

I haven’t got children, and I’ve only got one niece, and I can’t imagine that she’s likely to come and look after me... I remember us joking, one time, and me saying, oh well when I am an old woman you can come and looking after me and she said ‘not likely’, so I really don’t think so [discussion between Tessa and Ellen about her niece’s lack of practical skills]. So, no I don’t think there would be any support for me, I would be one of those little old ladies living in their houses on their own, surviving somehow... But you see, I don’t think I would want, if I was at that point, I don’t think I would want my life to be prolonged (Tessa, aged 58).

This extract highlights the importance of not only intergenerational relationships, but intergenerational relationships which can provide instrumental support. For Tessa living alone without support in old age is not a life she would want to live.

Several participants articulated concerns about the quality of formal care for older people:

I don’t have any problem ageing as I am now, it’s when you start thinking about things like, you know, going into an old people’s home, or even into sheltered housing or something like that, that one is afraid. Because my only experiences of those have just been so dreadful that I don’t think it would matter if I was a lesbian or I was straight, I just don’t want to go there (Jennifer aged 62).

My mother was in a care home for the last two years of her life. So I know what a good care home of that traditional sort can be. I mean, it was excellent. But, she didn't particularly want to be there. And I certainly wouldn't. And part of my philosophy is that I don't want to end up in any sort of care home (Iris, aged 61).

Both Jennifer and Iris are expressing concerns about care provision for older people, irrespective of sexuality, and not wanting to experience the same care (whether ‘dreadful’ or ‘excellent’). Several participants articulated combined concerns about both a lack of informal social support and the quality of formal social care for older people:

I've no family, they're all dead, no children, I never wanted any, no partner. And so there wouldn't be anybody there for me. And I can't imagine anything worse to be in hell hole in the armpit of a care home, where I'm abused or neglected. I'd rather die, thank you! So if ever I feel that physically or mentally, I'm on the downward slide, I definitely want to do something about it, because I can't see the point. I can't see the point at all and I feel strongly about it (Sally aged 73).

Sally's reasoning is based on a combination of factors: her increased need for formal care provision due to a lack of informal social support, including intergenerational support; and her vulnerability to the shortcomings of that provision where she could be exposed to abuse and neglect (as, sadly, many older people are, Biggs et al 2009). May has similar concerns, exacerbated by fears of heteronormativity and homophobia,

You lack that close family network, so obviously you are more isolated. I live in an incredibly amount of fear about my future. Not just as an older person. But as a gay older person. Institutions, they're very straight. My god I hope I don't have to go into a care home, I really do. It's all men and women, and I just can't imagine what it will be like. When I think about it, I find it quite scary. It frightens me that I am just going to be invisible, a nobody, that I am just going to be lost. And what I would want to do is just die... I just don't want to end up in an institution (May aged 64).

May is concerned about isolation, both in terms of a lack of informal (‘family’) social support, and in terms of formal older age care spaces. She perceives older age care institutions as ‘straight’, i.e. privileging heterosexuality (for more on this, see Westwood 2016b), where she will have to live alongside men, and where, as a gay woman (as she identifies), she will not be

recognised or valued (‘I am just going to be invisible, a nobody’). This fills her with fear, and informs her wish to die.

Stan is also concerned about the combination of a lack of social support and about formal care provision. His civil partner is in ill-health and Sam was not sure who would support him if his partner died,

Our friendship groups have actually diminished over the years ... I would be no different from the 70% of gay people, living alone, of a certain age, and where they don’t have children, and do not have immediate family around them. I could not ask my neighbours. (Stan, aged 61).

At the same time as being aware of a diminishing circle of social support, Stan is also concerned about formal care provision,

... I would not want to go through that level of distress....in a care home, where I would be in a minority, a) because I’m male and b) because I identify as being gay. And the care staff making assumptions and say ‘Sit next to Gladys, because she hasn’t got anybody’. And I’m thinking ‘I don’t want to sit next to Gladys, I’d rather sit next to Bob’. (Stan, aged 61)

Stan is highlighting here the importance of gender and sexuality in care spaces, where he would be a minority both as a man and a gay man. He is also describing his fears about embodied heteronormativity, i.e. being physically placed, or mis-placed as a heterosexual man (positioned ‘next to Gladys’). Phil does not want to share care spaces with women at all,

I am terrified of a nursing home where all the staff are female, and they treat me as if I fancy the women. Just awful... Not a woman in sight would be fine by me. I know that sounds awful. But... I just relate to men so much better... the vast majority of women that I know, pass me by, they’re just part of the scenery that I can’t avoid. (Phil, aged 62).

Several of the women participants were also concerned about the co-occupation of care spaces,

Some of that I saw in my mum’s nursing home, old blokes, just, leech, you know. ‘Oh, dykes, phew, give me half a chance, mate’. And when you’re old and weary you don’t want to be fighting that kind of crap off, really (Daphne, aged 60).

Daphne is describing here her fears of unwanted sexual advances by heterosexual men and feeling at heightened vulnerability to be able to resist such advances because of older age.

While there is much talk about the (older) lesbian and gay community, in reality, many older lesbians and gay men have very little to do with one another, and can fear being compelled into compulsory co-occupation at the end of their lives (Westwood 2015c). Many of the women in the larger sample expressed a wish for cooperative housing, with other women/lesbians. Alice, aged 60, yearns for the collectivist times of the 1980s and 1990s and mourns their passing (‘the thought of that never happening again, never being a part of it, to me is a bit like death’). She wants to live in cooperative housing with other lesbians and gay men, but there is not any. This has led to her plan,

If I can’t see that there is some kind of housing or community solution that would bring me into contact with other LGBT people, if I was stuck on my own, I’d much rather sell up and get a scruffy little villa on a Greek island, for six months or a year, and then kill myself (Alice, aged 60).

Alice is linking a lack of opportunity for collective housing and mutual support with her own wish to die, highlighting the significance of access to affective housing and social support resources, in this context for marginalised older people, but also more broadly for older people in general.

DISCUSSION

As noted in the introduction, the views of older people in general, and older LGB people in particular, are under-heard in the ‘right to die’ debate. This analysis has opened the door to engaging on these issues with older LGB people, and will hopefully encourage further research in this important area. The data emphasise the tensions and inter-relatedness of quality of life in older age and the participants’ envisaging a time when they might wish to end their own lives and/or be assisted in doing so. For some anticipated poor quality of life and/or poor quality of care informed their anticipated wish to have a ‘right to die.’ For others the wish to have such a

right was one to which they felt they should be entitled irrespective of quality of life issues. The need to surrender to a passive death was questioned by individuals who had lived their lives in anti-normative ways.

There was concern about the adequacy of support and services for older people in general and, more specifically, those which recognise, understand, validate and meet the diverse needs and identities of older LGB people in particular. Participants understood their sexualities as informing their relative lack of informal social support and in particular intergenerational support, which in turn increased their risk of exposure to formal services which would not meet their needs. This subset of participants was different from the total sample in that these particular participants had comparatively less access to intergenerational support than the main sample. As noted in the Methodology, more of this data subset did not have children than the full sample. Of the twelve participants in the subset, only two of the women had children, and none of the men had children. This is different from the full sample, where almost half of the women, and over a quarter of the men, had children. The role access to intergenerational support plays in a perceived ‘life worth living’ among older LGB people merits further enquiry.

It is also possible that intergenerationality plays a push-pull role in older (LGB) people considering ending their lives. Of the two participants in this data subset who did have children and grandchildren, one only wanted euthanasia if she was incapacitated and the other questioned whether she would be able to end her life in the way she wanted because of the effect on her children and grandchildren. It is possible, then, that while not having children might be a contributing factor in wanting to end one’s life in older age, having children may be a constraining factor in choosing not to do so. This affects older LGB people more than older heterosexual people, because older LGB people are less likely to have children. Older LGB people are thus disproportionately affected by a lack of intergenerational informal social support and by a lack of mainstream provision geared up to meet their needs and by a lack of

choice of alternative specialist accommodation with care. For a number of the participants in the subset, this informed their wishes/plans to end their lives.

The wish among older people to take one’s own life and/or for assisted dying and euthanasia needs to be disentangled from a formal health and social care system that is understood to be failing the old and very old in society. It is vital so that people who do decide to take their own lives are not turning to that option because it is the best of a very limited range of poor alternatives (Tulloch 2005 and 2015). There is an urgent need to address deficits in the care of older people and also to address the specific needs of marginalized individuals, including those of older LGB people (Westwood 2015b and c).

Many of the participants’ narratives engaged with issues which went beyond deficits in the care system. They linked assisted dying to issues of autonomy, choice and control, and constructed the denial of assisted dying as a site of oppression, particularly for those (older) individuals who are reaching the end of their lives. Several made it clear that they felt they would have to end their lives sooner than they might wish to, in order to make sure that they are still physically and/or mentally capable of doing so: ‘one is forced to give up what may be some good years of life in order to ensure that one can die with dignity’ (Davis 2015, p145-6). This, ironically, could mean that denial of lawful assisted dying (to protect the sanctity of life) can lead some older people to end their lives prematurely.

In this context, feminist analyses of vulnerability in relation to the right to die debate need to take into account not only issues relating to those individuals who may feel pressurised to end their lives. Older individuals who want to end their lives but are unable to do so themselves, and are prohibited in law from being assisted in doing so, could arguably also be vulnerable in the denial of a right to die, much as Shildrick (2015) has argued in the context of people with disabilities. There are thus contextual contingencies to notions of ‘vulnerability’ in relation to the ‘right to die’.

Lastly, several of the participants whose narratives have been analysed here questioned how death and dying in older age are socially and legally constructed. They challenged notions of a passive institutionalised death and dying and the norms and normativities associated with them. They understood denial of assisted dying and/or euthanasia as being a form of discrimination, whereby ‘irrational’ norms were imposed upon them in relation to how their lives ended. These narratives can be distinguished from those of participants who wanted the ‘right to die’ in the face of unavoidable suffering (acceding to juridico-medical authority). These different critical narratives are more closely aligned with radical positions of resistance to a passive, compliant dying subject in the juridico-medical model. Engaging with participants who have experienced and/or are continuing to experience social exclusions relating to live their lives against the heterosexist norms offers unique insights into the life-cycle norms with which they are implicated, including the disciplining of death and dying.

CONCLUSION

This paper does not offer solutions to the thorny moral issues associated with assisted dying. It does, however, highlight how some older people, especially marginalised older people, may be more vulnerable to ending their lives because of insufficient informal care and support and deficiencies in the formal older age care system. At the same time, older people, nearing the end of their lives, may also be disproportionately affected by a denial of access to assisted dying, which some may understand as undermining their embodied, autonomous, choice. There is a need for more research on the attitudes of older people (across the sexualities spectrum and other fields of marginalisation) towards assisted dying in order to include their voices in, and better inform, the ongoing debates about it.

NOTES

- (1) The chronological age ascribed to the onset of ‘old’ or ‘older’ age is culturally and spatially contingent (Gullette, 2011). For the purposes of my research I defined ‘older people’ as anyone aged over 60.
- (2) This article deliberately avoids the use of the word ‘suicide’ other than when using direct quotes. In the UK, ending one’s life was a criminal act called ‘suicide’ until 1961, when the Suicide Act 1961 (England and Wales) abrogated the rule of law whereby it was a crime for a person to ‘commit’ the crime of suicide. Under the Act, aiding, abetting, counselling or procuring the suicide of another was, however, deemed a crime, and remains one. This article uses terms such as ‘ending one’s life’ and ‘elective dying’ in order to disengage from associations with wrongful self-killing.
- (3) Women aged 80 and over are twice as likely to have dementia as men aged 80, and are four times as likely as men among people aged over 100 (Alzheimer’s Disease International, 2015).
- (4) One person in the full sample was polyamorous.
- (5) Interviews were conducted before same sex marriages were legalised in England, Scotland and Wales.

ACKNOWLEDGEMENTS

The author thanks the anonymous reviewers and the designated editor for their extremely helpful feedback on an earlier version of this paper.

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	Women	Men	Total
Total no of participants	36	24	60
Age range	58 to 92	58-76	n/a
Sexuality/ Sexual Identity	Lesbian (29) Gay (1) Bisexual (2) Ambivalent/non-labelling (4)	Gay (24)	60
Ethnicity	White (35) White British/South Asian (1)*	White (24)	White (59) White British/South Asian (1)
Single	14	11	25
Couple	22	12	34
Polyamorous	-	1	1
Children	17	7	24
No children	19	17	36
Grandchildren	13	3	14
No grandchildren	23	21	44

Table 1 Profile of participants from whole sample

*Dual heritage

	Women	Men	Total
Total no of participants	9	3	12
Age range	58 to 73	61-68	n/a
Sexuality/ Sexual Identity	Lesbian (8) Gay (1)	Gay (3)	12
Ethnicity	White (8) White British/South Asian (1)	White (3)	White (11) White British/South Asian (1)
Single	5	1	6
Couple	4	2	6
Polyamorous	-	-	-
Children	2	0	2
No children	7	3	10
Grandchildren	2	0	2
No grandchildren	7	3	10

Table 2 Profile of twelve participants from ‘right to die’ data subset