# Lived experiences of multimorbidity: an interpretative meta-synthesis of patients', GPs' and trainees perceptions

Dr Elizabeth Cottrell<sup>1§</sup>, Dr Sarah Yardley<sup>1</sup>

Address to which work should be attributed: Research Institute for Primary Care & Health Sciences, Keele University, Keele, Staffordshire, ST5 5BG

<sup>1</sup>Research Institute for Primary Care & Health Sciences, Keele University, Keele, Staffordshire, ST5 5BG

§Corresponding author: Email: <u>e.cottrell@keele.ac.uk</u> Telephone number: 01782 733991 Fax number: 01782 734719

#### **Abstract**

#### **Objectives**

Multimorbidity is an increasing challenge. Better understanding of lived experiences of patients, GPs and trainees, may advance patient care and medical education. This interpretative metasynthesis sought to i) understand lived experiences of patients, GPs and trainees regarding multimorbidity, ii) identify how similarities and differences in experiences should shape future solutions.

#### Methods

Empirical studies containing qualitative data and pertaining to lived experiences from our recent realist synthesis (PROSPERO 2013:CRD42013003862) were included. Following quality assessment, data were extracted from key studies to build an integrated analytic framework.

Data from remaining studies were utilised to expand and refine the framework through thematic analysis of concepts within and between perspectives.

#### **Results**

21 papers were included in the meta-synthesis. Analysis of 70 concepts produced five themes:

1) goals of care and decision-making, 2) complexity, 3) meeting expectations, 4) logistics and 5) interpersonal dynamics. The complexities of multimorbidity lead to shared feelings of vulnerability, uncertainty and enforced compromises. Barriers to optimal care/education included system constraints, inadequate continuity and role uncertainty.

## **Discussion**

There was little evidence of shared discussion of these challenges. Addressing these issues and more explicit exploration of the experiences of each group during interactions may improve delivery and satisfaction in care and education.

Key words: multimorbidity, lived experiences, patients, trainees, general practitioners

# 1 Introduction

2 Multimorbidity, 'the co-existence of two or more chronic conditions, where one is not necessarily more 3 central than the others'<sup>1</sup>, is an increasing challenge for general practitioners (GPs) as the population 4 ages, advances in medical science offer more management options and more people live for longer with multiple chronic diseases<sup>2,3</sup>. Multimorbidity is particularly common among deprived communities 5 so need is often mismatched with available services<sup>4</sup>. This exacerbates negative impact which 6 increases mortality<sup>5</sup>, hospital admissions<sup>5</sup>, polypharmacy<sup>6</sup>, psychological distress<sup>3</sup>, reduced quality of 7 life<sup>7</sup>, physical functioning<sup>5</sup>, poor management continuity<sup>8</sup> and patient empowerment<sup>3</sup>. 8 9 GPs should provide high quality, integrated and individualised patient-centred care, supporting and empowering patients to manage their long-term conditions<sup>3</sup>. Traditional single-disease based models 10 for guideline development<sup>6</sup>, service design and training threaten these expectations and may under-11 12 represent patients' priorities in measurements of quality. Challenges in achieving appropriate high quality primary healthcare for patients are echoed when establishing high quality workplace-based 13 education for trainees<sup>9,10</sup>. We recently conducted a realist synthesis (PROSPERO 14 2013:CRD42013003862<sup>9,10</sup>), that sought to answer 'what is known about how and why concurrent 15 16 healthcare delivery and professional experiential learning interact to generate outcomes, valued by 17 patients, general practitioners and trainees, for patients with multimorbidity in primary care?', During 18 the course of this work we identified that there was a paucity of critical analysis that investigated the 19 dynamic interactions between patients, GPs and trainees in the context of multimorbidity. In particular, 20 there was little consideration of the lived experiences of having or managing multimorbidity in each of 21 the groups, pertaining to not just what the individuals experience but also how they make sense of their situation and thus, how they live with it 11. Within the realist synthesis data was identified that 22 23 could be used to address these issues. Therefore we conducted a separate secondary analysis to 24 understand the lived experiences of multimorbidity of patients, GPs and trainees.

#### Aims

25

An interpretative meta-synthesis was undertaken to answer: 'What are patients, GPs and trainees'
lived experiences of multimorbidity and how can an understanding of the similarities and differences
between these be used to shape service and education delivery in the future?'. The study aimed to: i)

- 1 synthesise qualitative literature to develop an integrated understanding of all three groups' (patients,
- 2 GPs, trainees) lived experiences of multimorbidity, ii) identify, compare and contrast key concepts
- 3 between the groups, iii) develop understanding of the implications of similarities and differences within
- 4 and between the groups and iv) develop mid-range theories of the challenges of multimorbidity,
- 5 identifying areas for further research. Exploration of lived experiences, rather than just considering
- 6 processes of care, is likely to better identify ways to address patient dissatisfaction, inappropriate
- 7 management, increased efficiency and equipping future doctors to manage this complex issue.

#### Methods

8

13

23

- 9 This interpretive meta-synthesis represented a novel secondary analysis of literature identified for our
- 10 prior realist synthesis. As a secondary analysis of existing literature, ethical approval was not
- 11 required. ENTREQ statement guidance, designed to increase transparency in reporting the synthesis
- 12 of qualitative research, was followed<sup>12</sup>.

#### Synthesis methodology

- 14 The terminology to describe a synthesis of qualitative data originating from varied sources is complex
- and inconsistently used<sup>12</sup>. This is an interpretative meta-synthesis drawing on the seven steps of the
- meta-ethnographic approach described by Noblit and Hare<sup>13</sup>: i) develop a question, ii) search and
- 17 select studies, iii) read studies, iv) determine how studies are related, v) translate studies into each
- 18 other, vi) synthesise translations, vii) express the synthesis. The final stage of our review was to
- 19 develop mid-range theories of the challenges of multimorbidity. A mid-range theory is a theory of
- 20 limited scope that seeks to explain and interpret a specific set of phenomena, in this case the
- 21 meaning derived by our three groups from their lived experiences of multimorbidity. The
- 22 methodological detail of these steps follows.

#### **Searching and selection of studies**

- 24 The literature sample for this meta-synthesis was selected from our realist synthesis database which
- 25 contained published work relevant to multimorbidity in primary care with sub-focuses on
- education/workplace experiences and social processes<sup>9,10</sup>. The database contained papers identified
- 27 from an initial search undertaken on the 1<sup>st</sup> August 2012 with no date limitations and alerts were set to
- 28 identify new papers until 1<sup>st</sup> August 2013<sup>10</sup>. Both authors screened all empirical studies and original

- 1 realist synthesis data extraction sheets for qualitative studies regarding lived experiences. Sixty-four
- 2 papers were identified as being potentially relevant.
- 3 Included papers reported qualitative empirical studies and provided first order data on patient, GP
- 4 and/or trainee perspectives of their own or others' lived experiences of multimorbidity in primary care.
- 5 Exclusion criteria were if papers were non-empirical and/or non-qualitative studies, thus did not
- 6 contain first order data or were non-empirically derived opinion pieces (Exc1), or if they did not
- 7 contain detail about lived experiences of multimorbidity in primary care (Exc2). For the purposes of
- 8 this study, 'lived experiences' were defined as narratives, descriptions, or examples of patient, GP
- 9 and/or trainee stories/perceptions of their own 'real life' events or experiences. These lived
- 10 experiences were as accepted as first order data when reported through the use of direct qualitative
- 11 quotations (referenced to specific people) from patients, GPs and/or trainees. Second order data
- 12 which was also accepted consisted of narratives, descriptions or examples where a third party (e.g.
- 13 the authors of a study) was relaying the experience in their own words. It is accepted that even the
- 14 first order data necessarily represents individuals' perceptions of their experiences of living with
- 15 multimorbidity, as individuals chose, deliberately or subconsciously, to present these in a certain
- way<sup>14</sup>. It is not, however, possible to generate data on the meaning another person attributes to an
- 17 experience other than through their sharing of perceptions. After applying Exc2, no papers examining
- trainees' lived experiences remained. In order to identify trainee data to use for comparison, Exc2 was
- 19 relaxed for trainees only, such that papers had to refer to lived experiences of general primary care
- 20 teaching/learning, rather than specifically in relation to multimorbidity (see Figure 1). The decision to
- 21 relax the inclusion criteria was appropriate in this context due to the high prevalence of multimorbidity
- in primary care patients. Trainees' experiences of primary care will, by nature, include experiences of
- 23 multimorbidity, even if this has not been the explicit focus of the primary research.

#### Quality assessment

- 25 Full text papers which met inclusion and exclusion criteria (n = 25) were independently quality
- assessed by SY and EC using a five point 'strength score' adapted from Hammick et al<sup>15</sup>, see Table
- 27 1. Strength scores were allocated according to the reporting of the methodology and results, the
- study type did not automatically influence the score. Where differences existed between the authors'
- 29 allocated codes (3/25, 12%), by consensus the lower of the scores was given. Given the paucity of

- 1 the data available, to ensure as broad a view as possible of the lived experiences of each group, only
- 2 papers allocated the score S1 (n = 4) were excluded, thus 21 papers were included in the meta-
- 3 synthesis (see Table 2).
- 4 Figure 1: Flowchart detailing identification of papers for interpretative meta-synthesis
- 5 Table 1: Researcher derived strength score descriptors adapted for use in quality assessment
- 6 for secondary analysis
- 7 Table 2: Characteristics of included studies (empirical evidence of perspectives on lived
- 8 experiences relevant to multimorbidity)

#### 9 Data extraction: reading the studies

- 10 Information about study methodology and participants was summarised (see Table 2)<sup>16</sup>. First, the
- most recent highest quality papers for each of the three groups (patients<sup>17</sup>, GPs<sup>18</sup>, trainees<sup>19</sup>) plus one
- paper addressing experiences of two groups (patients and trainees<sup>20</sup>) were selected to develop an
- initial analytic framework. EC and SY read each paper to establish the context, coded direct
- 14 quotations (first order interpretations) to distinguish from other text (views of the authors i.e. second
- order interpretations), then identified and coded 'key concepts' using NVivo software<sup>21</sup>. Extracted
- 16 concepts were not predefined, rather these were developed 'in vivo' during the coding of the data.
- 17 Codes were organised into concepts and then were compared and assimilated to create 'key themes'
- 18 from which a consensus-based analytic framework was developed. Direct quotes, and relevant data
- 19 from these quotes, were extracted by EC or SY from the remaining included papers to populate and
- 20 refine the framework, which underwent iterative changes as necessary if new concepts emerged
- 21 (reciprocal translation). Second order interpretations were then reviewed and novel concepts added to
- 22 enrich the themes created from the first order interpretations.

23

#### **Establishing relationships between studies**

- 24 On completion of coding, SY and EC developed emergent themes. Concepts were grouped into
- 25 themes, and relevant data were reviewed (see Figure 2). Using thematic analysis, the perspectives of
- all three groups were described within themes, rather than outlining perspectives of each group
- 27 separately. This facilitated comparison of similarities and differences in perceptions about the same
- themes and consideration of different themes across the groups, perceptions about how the different

- 1 groups interacted with each other and how meaning-making or learning arose. It was noted if one
- 2 group gave their perceptions about the lived experiences of another group.

#### 3 Translating findings into each other

- 4 Through comparison of data extracted according to each concept and emerging theme, consistency
- 5 of views from and between each group could be determined. Divergent views were identified.

#### **6** Synthesising translations

- 7 Revisions to the themes were made to develop our own third order, 'line of argument' interpretations
- 8 of perspectives. During this process any identified similarities, differences and omissions, were noted
- 9 to classify themes as from individual groups, paired groups or from all three groups.

#### Results

10

19

- 11 After application of inclusion and exclusion criteria 25 studies were quality assessed, resulting in four
- being excluded. Of the 21 papers included; nine described lived experiences of patients, five of GPs,
- 13 five of trainees, one of both patients and trainees and one of both patients and GPs, see Figure 1.
- 14 Seventy concepts were initially extracted from first and then second order data and developed into 16
- 15 initial third order themes (see Figure 2). These were eventually organised into five final third order
- themes: 1) goals of care and decision-making (patients and GPs), 2) complexity (patients, GPs,
- trainees), 3) meeting expectations (patients and trainees), 4) logistics (patients and GPs), 5)
- 18 interpersonal dynamics (patients, GPs, trainees). These themes are presented below.

#### Goals of care and decision-making

- 20 Patients and GPs both described concepts relating to goals of care and decision making. Notably,
- 21 there was an absence of explicit consideration of this among trainees. Both GPs and patients shared
- 22 understanding between GPs and patients that management should not be solely dictated by arbitrary
- 23 targets. GPs recognised that medical goals of care may not match patient goals<sup>22</sup>. Consequently they
- 24 realised that management needed prioritising according to the impact of conditions on the patient's
- 25 life<sup>22</sup>. This concept was recognised by patients who explicitly reported having to function<sup>17</sup> and not
- 26 give up<sup>23</sup>. However, patients voiced that this may involve them making compromises while setting

- goals between life-threatening versus function-threatening conditions<sup>24,25</sup> and/or quality of life versus
- 2 function<sup>24,26</sup>; '...I found more concern or anxiety about the problems to do with my back and mobility
- 3 than I have about my diabetes, although the side effects from diabetes can kill you...<sup>25</sup>. Although, this
- 4 choice of function or quality of life versus longevity is implicit in GPs' acknowledgement of the need to
- 5 individualise priorities, the stark nature of this choice was not voiced explicitly by the professionals in
- 6 the papers examined. More specific examples of this type of compromise was illustrated by patients
- 7 choosing between side effects versus benefits of medication <sup>24,26,27</sup> and maintaining independence <sup>24</sup>,
- 8 with its associated risks, versus going into care<sup>23</sup>. Such compromises and priorities shifted depending
- 9 upon circumstances<sup>18</sup> and, for example, in the nature of symptoms e.g. pain; 'Whatever hurts the
- most is what is taken care of...,<sup>26</sup>.
- 11 Patients and GPs both recognised that patients are autonomous. Patients reported making drug
- 12 choices outside of consultations<sup>23,25</sup> and GPs recognised the risk of undermining patients' coping
- mechanisms by enforcing medical intervention<sup>28</sup>.
- 14 Both patients and GPs shouldered responsibility for risks and decision making. GPs felt that they take
- responsibility for risk management<sup>18</sup> and patients recognised that they should take responsibility for
- decisions<sup>23</sup>. Although they felt a responsibility for risk, GPs indirectly acknowledged that patients do
- make decisions as they describe their role in adequately informing patients to make decisions<sup>29</sup>,
- which may involve refereeing between specialist opinions<sup>28</sup>. This role was challenged by the health
- 19 literacy of some patients<sup>29,30</sup>. There was a shared recognition of the need to individualise decisions
- and the potential for individual care plans to achieve this<sup>31</sup>. Although trainees expressed feelings of
- 21 responsibility for patients' care and some anxieties about this, this was more in the context of lack of
- 22 knowledge leading to fear of causing harm in general<sup>20</sup>, rather than specific to the responsibility for
- 23 ongoing complex care which is implicit in managing multimorbidity.

#### Complexity

- 25 GPs were alert to patients' struggle with the burdens and chaos associated with multimorbidity<sup>28,30</sup>;
- <sup>26</sup> 'Their care takes all week'<sup>28</sup>. However, the loss of function and resulting dependence on others,
- 27 raised by patients<sup>23-26,32</sup>, was only explicitly mentioned by GPs in the context of the impact on carers<sup>28</sup>.

```
1
       A prominent issue contributing to complexity of multimorbidity for GPs was the (possible) presence of
       cognitive impairment<sup>22,28</sup>, depression<sup>28</sup>, somatisation<sup>18</sup> and, as described later, isolation; 'The other
 2
 3
       problem with a percentage of these patients is that they are...cognitively impaired...it's very difficult to
       explain things...and you have to explain things again and again...'28. GPs need to consider the
 4
 5
       patient's capacity to engage with the complex discussions required to explore management options<sup>22</sup>.
       There was shared recognition among patients<sup>23,25</sup>, GPs<sup>22,29</sup> and trainees<sup>19</sup> about the complexity
 6
 7
       introduced by the obscurity of clinically relevant presentations, and normal aging or reactions to
 8
       difficult circumstances. Patients may be hyper-vigilant for symptoms of worsening or new problems
 9
       and GPs described diagnostic uncertainty in the face of multimorbidity with the knowledge that
10
       presentations vary between patients; 'The difficulty then comes in trying to diagnose, well, are they
       depressed or not? They're upset, frustrated, angry...confused about these chronic conditions, which
11
       they didn't have, that can be a bit different from depression' (GP)<sup>22</sup>. Although patients and GPs
12
       shared an appreciation of the complexities in identifying and managing multiple concordant and
13
14
       discordant problems, in the literature examined, GPs did not explicitly recognise that the patient's
15
       hyper-vigilance for symptoms may arise from the patients struggling to determine what is significant
16
       and not significant.
17
       Patients and GPs recognised that the problems of one condition can be compounded or magnified by
       the presence of others, and the negative impact of drugs may be multiplied in multimorbidity<sup>22-25,27,28</sup>.
18
       The presence of widespread single-disease based approaches<sup>22,31</sup> made patients feel overwhelmed
19
       by the diagnoses and created problems for GPs in trying to create coherent management plans<sup>28</sup>,
20
       particularly among older patients<sup>29</sup>. Indeed patients can feel confused, disempowered and
21
       increasingly anxious as a result of conflicting advice for different problems and regular
22
       reviews<sup>22,26,28,32</sup>, a situation which may further increase the risk of receiving mixed messages<sup>33</sup>.
23
24
       Prescribing in the existence of multimorbidity, particularly among older adults, was highlighted as a
25
       particular problem by both patients and GPs who expressed innate discontent with the existence of
       polypharmacy<sup>25,27,28,33</sup>; '...the third pill might be the killer, you know what I mean?' (patient)<sup>27</sup> and
26
       '...we're poisoning our patients' (GP)<sup>28</sup>. GPs highlighted the need to balance risks versus benefit in
27
       prescribing decisions<sup>29</sup>, particularly noting the morbidity caused by medications themselves<sup>28</sup>.
28
29
       However, the issue for patients was wider than the biological impact or risks. The impact on patients'
```

- 1 lives was also an issue, particularly if they felt their life revolved around taking medication<sup>33</sup>. Again,
- 2 the function versus longevity compromise was pertinent; 'I don't like taking pills, but I'd rather take
- 3 pills and stick around for a while...<sup>26</sup>. However, a clear solution to these issues was not articulated.
- 4 One option could be to leave clinicians to devise individualised but, due to the current lack of
- 5 evidence in multimorbid patients, more subjective, rather than evidence- and/or guideline-based care.
- 6 However this would further increase the risk of mixed messages to the patient, which they do not like,
- 7 and, by nature, it would promote non-standardised care. Although seen as appropriate at times 18,
- 8 deviating from the guidelines in the presence of multimorbidity did not sit comfortably with all GPs<sup>28,29</sup>
- 9 and some GPs perceived variations in practice as undesirable <sup>29</sup>. Trainees did not explicitly discuss
- 10 polypharmacy, perhaps because in the papers examined, some of the experiences were in the
- 11 context of applying uncertain knowledge in relatively protected environments: '...this patient presents
- with these complaints, I find this and that on physical examination and, er, I am thinking of prescribing
- 13 this...<sup>19</sup>.
- 14 Although none of the papers specifically addressed trainees' experiences of multimorbidity, trainees
- 15 voiced the general complexities inherent in primary care from seeing an unscreened population in
- which certain answers to patients' problems, or the diagnoses themselves, are not always clear<sup>34</sup>.
- 17 Inherent in the primary care population are a large proportion of people who have multimorbidity and it
- is therefore likely that this contributes to the trainees' perceptions of complexity in this setting.
- 19 However, it is notable that trainees did not recognise the role of multimorbidity in their perceptions of
- 20 complexity, which possibly indicates a missed opportunity for them to identify coping strategies
- 21 through explicit discussions with the experienced patients and GPs they interact with. Although
- trainees reported using guidelines to support their decisions<sup>35</sup>, they did not explicitly acknowledge the
- 23 limitations of guidelines, in general, and in the context of multimorbidity. Nor was there evidence of
- 24 trainees articulating an appreciation of managing multiple discordant problems. However, trainees did
- 25 indicate that the improved understanding of patients' lives inherent with working in primary care
- promoted more pragmatic choices for delivering holistic care<sup>36</sup>, which implies an understanding that
- 27 management decisions are not black and white.
- 28 Patients, GPs and trainees expressed different coping mechanisms to manage the complexities
- 29 described. Patients seemed to cope by developing and/or maintaining a sense of control and/or

- 1 routines<sup>17,23,25,26</sup>. Patients also expressed self-vigilance for new diagnoses<sup>25</sup>. They thought written
- 2 information would help<sup>26</sup>, but only if it was pertinent to the patient's situation and level of
- 3 understanding<sup>32</sup>. There was evidence that both patients and GPs balanced the difficulties associated
- 4 with complex treatment regimes with the recognition of single management solutions that can help
- 5 multiple problems<sup>22,25,32</sup>. The solutions offered by GPs recognised the need for a whole patient
- 6 approach from diagnosis to end-of-life<sup>18</sup>, because patients and GPs recognise that additional
- 7 complexity is introduced by some patients' circumstances (e.g. deprivation)<sup>17,30</sup>. However, the
- 8 overwhelming number of issues made some GPs resort to a reductionist 'additive-sequential model'<sup>22</sup>.
- 9 Assuming that order of presentation is a proxy for priority, in this model GPs managed each concern
- 10 presented to them in turn until the consultation time ran out. Although some trainees described the
- 11 complexity and challenge of primary care as having a negative effect on their career choice to be a
- 12 GP<sup>34</sup>, others wanted to increase their exposure to complex cases<sup>37</sup> and to take responsibility for
- patient care <sup>19,37</sup>, albeit in the presence of adequate support and feedback<sup>34</sup>.

### **Meeting expectations**

- 15 Patients and trainees shared the experience of having an awareness of how they might be perceived
- 16 by others, particularly within the primary care practice. Patients explicitly reported feeling judged and
- 17 concern about negative perceptions of others, which may be enhanced by multiple review
- 18 appointments which are commonplace when traditional care models are used to manage
- multimorbidity: 'I go in and feel as if the receptionists...must be saying to themselves "Oh her
- 20 again"...<sup>17</sup>. Both patients and trainees wanted to be seen as being useful. Patients gained satisfaction
- 21 from being involved in the students' education through an altruistic investment in doctors of the
- future<sup>20</sup>. Trainees valued their involvement in patient care and were explicit about wanting to be seen
- as being useful, rather than in the way<sup>19,20</sup>, and to be taken seriously by GPs<sup>19</sup>.
- 24 Trainees reported a challenging balance in expressing the correct level of emotion and/or
- 25 vulnerability. On the one hand, trainees were concerned that too much focus on the human side
- detracted from the expected perception of a doctor to focus on the scientific aspects of care<sup>20</sup>. On the
- 27 other hand trainees recognised that their perception of GPs was not undermined by the doctor
- admitting a knowledge gap or emotional response and this empowered trainees to follow suit 19.

- 1 Perhaps in response to an awareness of being under the scrutiny of others, patients and trainees
- 2 explicitly remarked on actively 'keeping up appearances'. For patients this involved maintaining a
- 3 social role and routine<sup>23</sup>, which may require overcompensation for illness,<sup>17</sup> and for trainees this
- 4 involved managing uncertainties while maintaining an appearance of competence to both patients and
- 5 GPs<sup>20,34</sup> and/or wishing to take responsibility despite their uncertainties<sup>20,35</sup>. However, the challenges
- of 'keeping up appearances' was also highlighted 17, perhaps indicating the need for supervising GPs
- 7 to actively promote patients and trainees to be themselves or to invite them to drop their facade at
- 8 times to ensure all their needs are attended to. Physical environment, for example, a dedicated
- 9 consulting room, was recognised as a tool through which trainees achieve their desired identity<sup>19</sup> and
- this, in some ways, echoes the sentiments of patients whose goal is to continue living in their own
- 11 home.

12

#### Logistics

- 13 Patients and GPs had a shared understanding of the logistical difficulties that multimorbidity fostered
- 14 for patients. GPs highlighted the inadequacy of traditional primary care service delivery methods
- which risk fragmented care<sup>38</sup>. Both GPs and patients identified barriers to achieving relational
- 16 continuity of care which included technology<sup>22,38</sup>, availability of the patient's 'usual' doctor<sup>26,38</sup> and
- 17 accessing appointments; '...you have to...make an appointment to be sick...'38. Lack of relational
- 18 continuity, was disliked by some patients<sup>33,38</sup>. However, at least for some patients, adequate
- informational continuity could mitigate against disrupted relational continuity; '...the notes are carefully
- 20 kept and they pick it up quite quickly...<sup>38</sup>.
- 21 Multiple problems often resulted in multiple appointments<sup>23,26</sup> for which patients and GPs recognised a
- high level of organisation was required <sup>22,33</sup>. This compounded the aforementioned appointment
- 23 access issues 17,38. Patients 26,33 and GPs 22,28,31 raised the issue of time limitations in consultations; 'too
- 24 many things to talk to the doctor about in such a short time...<sup>33</sup>. Although GPs recognised that
- 25 patients get frustrated with multiple monitoring appointments<sup>22</sup>, neither group expressed recognition of
- 26 how the other may feel. There was discordance in the reactions of patients and GPs regarding the
- 27 issue of time limitations within consultations. Time restraints left patients feeling 'annoyed' and
- inadequately listened to<sup>26</sup>. GPs who spent extra time to undertake required activities felt increasingly
- 29 overburdened by the workload<sup>28</sup>. GPs felt they had insufficient time to provide care for multiple

- 1 problems<sup>22</sup> and recognised time as a barrier to providing desired holistic care<sup>30,31</sup> and/or to motivate
- 2 patients to change<sup>22</sup>. As a result, one GP described 'constantly....rationing out time'<sup>30</sup>. Some GPs
- 3 responded to these pressures by avoiding proactive problem seeking<sup>28</sup>, for fear of unearthing
- 4 problems they could not manage or that would require additional, non-existent time<sup>30</sup>. This may widen
- 5 the gap between the holistic, patient-centred care they wish to provide and the care they can and do
- 6 provide; '....you don't say anything, because you know you're at the beginning of the afternoon...'28.
- 7 Despite clear dissatisfaction among patients and GPs about the logistics of managing multimorbidity,
- 8 ideal and encompassing solutions were elusive. GPs valued support for holistic patient care from
- 9 specialists<sup>28</sup> but cautioned that gaps in patient care can occur if specialists do not take responsibility
- 10 for patients<sup>28,31</sup>. Patients and GPs suggested that written information<sup>26</sup>, education<sup>28</sup> or improved
- 11 clinical resources (e.g. care plans)<sup>26,31</sup> may help to empower, reduce distress and improve care
- delivery for patients with multimorbidity<sup>22</sup> but patients recognised the variable impact that
- multimorbidity has on those affected by it<sup>25</sup> and acknowledged that one service design will not fit all<sup>26</sup>.
- 14 Other strategies suggested by GPs included promoting relational continuity<sup>22</sup> and planning
- 15 interactions, possibly with named individuals<sup>22,28</sup>.

#### Interpersonal dynamics

- 17 The importance of appropriate interpersonal dynamics was identified in data from all three groups. All
- 18 groups reported positive experiences. Good experiences of information provision and support were
- valued by patients; 'Dr X is a very, very good doctor ....He explains things to you'33. Trainees also
- valued attentive interactions with GPs<sup>34,35,37</sup>, particularly when sources of help were clear<sup>19</sup>, the
- 21 individual to provide assistance could be chosen according to the query<sup>34</sup> and the optimum learning
- environment was developed through discussion <sup>19,37</sup>. The latter point draws a parallel with, and
- 23 requires the same skills as, providing patient centred care. Further, interactions with supervising GPs
- meant that trainees used them as role models, to learn medical practice and about the career<sup>19</sup>.
- 25 Trainees actively reflect on the interpersonal dynamics they observe between GPs and patients, for
- 26 example, by recognising the negative impact of problematic communication; '...patients just hear a
- 27 jumble of a lot of terms...you see those people looking very anxious at first and then things just go
- 28 horribly wrong...<sup>19</sup>.

- 1 The co-existence of trainees and patients in a consultation with a GP seems symbiotic for both to gain
- 2 knowledge. Patients perceived that trainees provided warmth and humanity<sup>20</sup> to consultations and
- 3 asked the questions that patients also wanted answers to<sup>20</sup> and trainees learnt through hearing GPs'
- 4 explanations to patients<sup>37</sup>. Although GPs recognised the value demonstrating a personal interest in
- 5 patients<sup>30</sup>, GPs highlighted the difficulty of interacting in this way in the presence of multimorbidity<sup>30</sup> as
- 6 issues may be raised that GPs feel ill-placed to manage<sup>30</sup>. Unsurprisingly, therefore, interpersonal
- 7 dynamics was often discussed in the context of problems.
- 8 At the most basic level, patients and trainees apparently shared, unspoken, the negative impact of
- 9 insufficient interpersonal interactions; isolation. Trainees reported negative experiences at clinical<sup>19</sup>,
- 10 educational<sup>37</sup> and/or personal<sup>37</sup> levels. Perceptions of isolation were fostered by difficulties integrating
- with the team<sup>34</sup> and from the primary care environment itself; '...being in a room, and you can't really
- leave...<sup>34</sup>. Associated with this, perhaps, are trainees' uncertainties about their level of supervision
- and/or feedback; 'I sometimes wonder if I don't get enough feedback when things go wrong...'34.
- 14 GPs recognised the risk of isolation for patients but feared that becoming a patient's primary source of
- social contact risks undermining the patients' self-efficacy<sup>30</sup>. However, patient data revealed that this
- does not represent comprehensive understanding of the nature of isolation. Patients did not have to
- be alone, but could feel isolated if they believed those people did not (want to) understand their
- problems; '...You're all alone....Even within the family they know I've got this problem and...we don't
- 19 even talk 'bout it...'23.
- 20 Patients described breakdowns in communication with healthcare professionals making them feel
- 21 unheard; '...for months he [the GP] would pay no attention to me... he'd say \_No, it can't be...<sup>33</sup>. This
- 22 is perhaps more likely in the context of multimorbidity, when, as previously identified, the issue of
- 23 identifying pathology from normality can be complicated. Consequently, management plans
- sometimes ill-matched patients' desires; 'I have been trying to convince my doctor that I don't need
- 25 the cholesterol medication...<sup>24</sup>. Sometimes patients felt they were communicating at cross-purpose
- due to the complexity of their care<sup>33</sup>, inadequate documentation<sup>38</sup>, and/or lack of a coherent message
- 27 resulting from a breakdown in relational continuity; '...one says you can... one says you can't... they
- don't seem to all work with the same information'33. The evidence suggested that GPs were alert to
- 29 this risk; 'All doctors should speak with one voice', GPs also recognised other virtues of relational

- 1 continuity, such as enhanced impact of advice given and patients being '...a bit more open with
- 2 you...<sup>22</sup>. Trainees too, identified value in achieving long-term follow-up of patients and the richness to
- 3 understanding that this brought<sup>19</sup>.
- 4 Despite apparent shared recognition among the three groups about the necessary features of
- 5 successful interpersonal dynamics, barriers to achieving this include lack of time<sup>26</sup>, breakdowns in
- 6 continuity of care<sup>38</sup> or learning supervision<sup>37</sup>, concerns among GPs about hidden messages given or
- 7 harm caused by management options and/or decisions (e.g. deprescribing)<sup>28,29</sup> and similar concerns
- 8 among trainees about doing wrong/causing harm<sup>20</sup>. Underlying many of these issues may be the
- 9 different values and priorities held by each individual during the consultation and about management.
- 10 Such differences may not be voiced during the consultation 23-25,27. Patients appeared to seek a
- balance between medical risk of harm versus functional problems<sup>32,33</sup>. GPs recognised this and the
- need to focus on functional problems to address patient goals<sup>31</sup>. However, GPs described their own
- balancing act between stepping-out of their medical role enough to listen to other, social problems<sup>30</sup>,
- discouraging patients from becoming dependent on them<sup>30</sup>, maintaining equitable and sustainable
- 15 care for all patients<sup>30</sup> and addressing whether what patients want is appropriate<sup>18</sup>; '... it's always a
- matter of finding a balance between what the patient wants, the burden of the treatment for him, and
- the potential good you think it will do. And what does the patient experience as good?<sup>18</sup>.
- 18 Trainees recognised that primary care provided a good platform to identify patients as people and to
- 19 recognise that their behaviour may not match planned care; '...you have a better insight into what
- 20 causes health problems...you get to know the person better which has a huge impact on a person's
- 21 health generally...response to treatment, whether he takes his treatment...a more realistic attitude;<sup>36</sup>.

#### Overarching interpretations and implications

22

- 23 Through comparing the lived experiences of patients, GPs and trainees regarding multimorbidity a
- 24 number of common concepts were identified and were developed into themes. Within themes,
- 25 perceptions about each concept were not necessarily shared between the groups. Complexity,
- 26 uncertainty and the poor fit of current health services to the needs and priorities of patients were
- 27 dominant messages from the included papers. All three groups indicated that they felt a responsibility
- 28 to manage patients' problems but all also felt overwhelmed at times from the management strategies
  - involved in providing best-evidence based care (patients), managing a multitude of problems within a

- 1 limited time (GPs) and managing patients who could be coming in with anything and feeling unable to
- 2 manage them (trainees). Examining the literature altogether has also demonstrated that the
- 3 experience of all three group includes prioritising how others perceive them and addressing the
- 4 (perceived) expectations of others ahead of addressing their own needs and difficulties at times.
- 5 GPs need to recognise their significant role in shaping positive lived experiences of patients and
- 6 trainees, through direct interactions, by one group i.e. trainees, observing the GP's interactions with
- 7 another, i.e. patients and by facilitating patients and trainees to function in their most desired
- 8 environment (e.g. home or dedicated consulting room, respectively). To maximise their positive
- 9 impact, GPs thus need the time to provide adequate explanation and support of both these groups of
- 10 people, allow adequate two-way interaction to provide space for patients and trainees to be as
- 11 autonomous as they can be and to appear open to patients and trainees to invite a sharing of their
- own priorities. To do so, GPs need the time and space to probe for less easily raised issues to ensure
- 13 that management and learning plans are individualised to the patient and trainees needs,
- 14 respectively. In optimising clinical and teaching settings, there needs to be a recognition of the
- 15 importance of the patients' and learners' physical environments in their self-identity, that patients and
- learners can be disempowered by being forced into situations that they do not feel comfortable with
- 17 (i.e. patients leaving their own home and learners not having their own consulting space).
- 18 GPs and patients identified the need to have malleable management goals and priorities that need to
- be individualised to the patients' context and priorities. However, to provide this requires explicit
- 20 discussion of the compromises between longevity and function that may result from individualised
- 21 plans. These issues were not considered within the trainee-focused data examined as part of this
- study and notable among the GP literature examined was the lack of vocalisation of the stark nature
- 23 of the compromises between longevity and function or quality of life that are necessary for truly
- 24 individualised care.
- 25 This synthesis has identified that patients, GPs and trainees all have to deal with internal conflicts.
- Patients are conflicted by, on the one hand, wanting to keep up appearances and maintain their
- 27 social, domestic and occupational roles as much as possible, yet also feel isolated by the lack of
- 28 (apparent) understanding of their problems by others. Data from both patients and GPs highlights the
- 29 perceived value of individualised care based on the patients' contexts, preferences and priorities;

1 indeed, patients sometimes strived for this even without the support of healthcare professionals by 2 adapting management plans to better suit them. However, examining all the data reveals a potential 3 for conflict within GPs with regards to providing individualised care. To do this requires a deviation 4 from guidelines, which is something that some GPs embrace, but others fear, and it may result in non-5 standardised care. The latter situation can be viewed negatively probably due to the perceived risk of 6 enhancing inequality and patients do not like getting incoherent plans, which may be more likely if, 7 owing to a lack of empirical evidence in the context of multimorbidity, individualised care is more 8 subjective. Finally, the data regarding trainees appears to reveal potential conflict. Like patients, 9 trainees like to have their own room or space from which they can perform their desired roles, however, the price for this space may be physical or emotional isolation 19,20. This review has 10 11 highlighted that a means to deliver individualised, non-standardised care that is acceptable to 12 patients, GPs and to the wider population is necessary, but a solution to this was not forthcoming. The 13 type of care necessary to meet all of the needs and expectations of patients with multimorbidity, is 14 complex and requires GPs and trainees to have the expertise and time to raise such issues, manage 15 uncertainties and to encourage candid participation in consultations by all involved. A key element of 16 it this is facilitating all three groups to have adequate autonomy. Patients need to remain autonomous 17 to contribute to their management planning, GPs need to be autonomous to deviate from guidelines and provide individualised care and, as both the key papers which included trainees highlight 19,20, 18 19 trainees need to be supported but given adequate information and space to feel that they can be 20 clinically autonomous in order to encounter the pertinent complexities and challenges and thus learn 21 ways to manage patients with multimorbidity during their future career, but they also need to be able 22 to be autonomous when planning their learning as well.

#### Figure 2: Initial 16 third order themes (capitals) with summary of associated concepts

#### Discussion

23

24

25

#### Synthesis output

This interpretative meta-synthesis identified five themes that summarise the lived experiences of patients, GPs and trainees of having or managing multimorbidity in primary care. This review has highlighted that there is no unifying, single story of lived experience with regards to multimorbidity,

within or between the three groups. However, comparison of the themes highlights that all groups 2 face similar issues, albeit in different circumstances. All groups recognised complexity in primary care, 3 and in particular managing multimorbidity. They all faced difficulties arising from uncertainties in 4 identifying abnormality from normality and identifying the 'best' management options or the 'right' 5 answers. Specifically, compromising between longevity and function was relevant to many of the 6 difficulties described by patients (who explicitly raised this) and GPs (who alluded to this). All groups 7 acknowledged the need to take, or hold, responsibility and all were concerned about being viewed negatively. Some of the parallels between the trainees and the patients, with regards to the way they are perceived 19,20, may reflect the relative power and positioning of both these groups. However, as Ashley et al highlight, patients do not always see themselves as equal to trainees who they perceive to be more knowledgable<sup>20</sup>. Thus explicit discussion about the expectations and value of all parties 12 involved in discussions (both clinical consultations and educational support) may help to level the 13 ground and promote shared development of management and educational plans. This may also help 14 to avoid inappropriate disempowerment of both trainees and patients, which, for the latter, may already be an issue as a result of their illness<sup>17</sup>. Instead GPs should strive to identify the ways in 16 which the functional and emotional problems experienced by patients and trainees may be addressed. From the data examined, this seems to be an area that is less attended to within GP's 18 lived experiences than the logistics and complexities of clinical management of patients. Both patients 19 and GPs were battling with the other party having different priorities and values, although 20 fundamentally the underlying concerns were similar (e.g. disliking polypharmacy but fear of deviation from recommendations, the potential for patient dependence on others, the need for supported 22 autonomy and the risk of feeling overwhelmed). Barriers to effective care and/or education were recognised by all groups and included breakdowns in relational and/or informational continuity, limited 24 time and inadequacies of current primary care service models to accommodate accessible, long-term, 25 consistent, efficient interactions for multiple problems. However, this synthesis has revealed that 26 relational continuity, although seen as ideal by some patients, GPs and trainees, was particularly valued by GPs<sup>18</sup> and trainees<sup>19</sup>, but was not necessarily seen as essential by patients, particularly in the presence of robust informational continuity with single, coherent management approaches. Indeed, proposed solutions to the problems identified by all three groups often involved each party having clear role parameters and being equipped with adequate information, tailored to the

1

8

9

10

11

15

17

21

23

27

28

29

1 individual's needs, in written format. Traditional models of care were identified by patients and GPs as 2 being inadequate to deliver the individualised care required to address the needs and priorities of 3 patients with multimorbidity and to accommodate time for complex discussions of risks versus benefits 4 in the context of that specific patient, A major revision of the nature and delivery of healthcare may be 5 needed to meet patients' expectations and to allow GPs to provide care in a manageable way. The 6 coexistence of trainees and patients in GP consultations appeared to have symbiotic benefits. 7 Trainees are viewed positively by patients, perhaps through shared experiences of uncertainty, 8 vulnerability, feelings of isolation and the need to learn. Both patients and trainees gain confidence 9 and self-worth by being involved in the care/education of the other. However, there was no evidence 10 of explicit dialogue between patients and trainees that acknowledged these shared experiences in 11 general, or specifically focussing on multimorbidity. 12 Most notable in its absence was the lack of papers specifically addressing trainees' management of 13 multimorbidity. By nature, training situated in primary care raises many issues that are relevant to 14 multimorbidity, but the absence of focussed consideration of this by trainees suggests solutions to the 15 problems identified are distant, and current trainees may be no better equipped to deal with the complexities. This is an issue that has previously been noted<sup>39</sup>. Also notable was the scant evidence 16 17 of acknowledgement of each group's experience and thus lack of realisation that all parties may be 18 experiencing similar difficulties. 19 Linked to the finding from this review that there is no single experience of multimorbidity within and between groups, Sinnott et al<sup>40</sup> conducted a meta-ethographic synthesis of qualitative data pertaining 20 21 to the conceptual understanding of the challenges of multimorbidity from ten studies reporting GP 22 perspectives. They also identified the problems of a generic approach to service delivery and 23 described four areas of challenge: disorganisation and fragmentation of healthcare; inadequacy of 24 guidelines and evidence-based medicine, challenges in delivering patient-centred care and 25 challenges in shared-decision making. While this is valuable, the authors themselves recognised the

need to further understand the challenges of multimorbidity from the patients' perspectives for

effective interventions to be developed. This is particularly so as patient-centred care and shared-

decision making are necessarily relational, and the organisation of healthcare is clearly a practical

26

27

- 1 challenge for patients as well as GPs. Training future doctors to work in ways that consistently deliver
- 2 high quality individualised care is also a significant challenge in need of address.
- 3 Other studies have highlighted the inadequacy of traditional, single disease based models of service
- 4 delivery in the context of multimorbidity<sup>41,42</sup>. Barnett et al<sup>43</sup> challenge the use of single-disease
- 5 frameworks to configure care, research and education arguing that this framework is unfit for purpose.
- 6 Instead they recommend the development of interventions for personalised comprehensive continuity
- 7 of care.

19

21

22

23

24

25

26

27

28

29

- 8 Supporting these findings, Noel et al<sup>33,44</sup> explored patients' views on self-management, identifying
- 9 multiple examples of problematic interactions with GPs. Also relevant are the findings of Fortin et al<sup>45</sup>
- 40 who identified that psychological stress increased with increases in functional impact of morbidities
- which in turn could impact negatively on patient engagement. Further, Kuluski<sup>46</sup> compared patients,
- 12 primary care doctors and care givers' goals in the context of multimorbidity and found that although
- 13 symptom alleviation and maintaining health goals were similar, aligned of goals deviated in the
- presence of functional and cognitive decline. This work, in addition to the results of this synthesis,
- 15 highlights the need for even greater investment in interactions and a better focus on holistic care to
- maximise patient health and satisfaction. This is a sentiment that has been echoed by a recent report
- by The King's Fund, which recognises that remaining at home and 'socially engaged' and being able
- to fulfil expected roles, are important aspects of wellbeing and quality of life for older people<sup>47</sup>.

#### Strengths and limitations

20 We are not aware of other studies synthesising qualitative data of patients or trainees, nor any that

examine all three groups concurrently. Meta-synthesis is a valuable approach that draws together

different elements relevant to a question or problem in order to develop new reasoning or

understanding. Synthesising qualitative data brings a richer understanding of the topic than reading

separate papers individually. This meta-synthesis excluded papers which only contained descriptions

or recommendations without any provision of empirical data. Although this may limit the amount of

data included, it ensures the results are not based on opinion but empirical evidence. In order to

capture a breadth of experience, only papers with a strength rating S1 were excluded. It could be

argued that those with S2 rating should also be excluded, however this only applied to one paper

which reported trainee data, already sparse, the information contained did provide some novel

- 1 insights, indicating that more robust trainee studies are likely to support the conclusions of this
- 2 synthesis. Clearly, only published information can be synthesised. Trainee papers that were not
- 3 specifically relating to multimorbidity had to be included as there were no papers specifically focussing
- 4 on this aspect. Although this may be viewed as problematic due to the lack of explicit focus and thus
- 5 potentially the omission of certain complexities specifically relating to multimorbidity, due to the
- 6 prevalence of multimorbidity in primary care, the lived experiences of trainees reported in these
- 7 papers will certainly have included experiences of patients with multimorbidity. Omissions identified
- 8 within the synthesis do not necessarily represent lack of awareness, knowledge or understanding
- 9 among each group, but rather a lack of published data about this, and hence areas for further
- 10 research.

11

#### Implications for clinical practice and research

- 12 To move service and education delivery forwards there were fundamental elements that all groups
- agree would form a successful model including; clear role boundaries, long-term, individualised and
- 14 planned interactions and with adequate, tailored information.
- 15 In clinical interactions, discussion of conflicting recommendations for different problems (or a
- 16 perception of this) should be explicitly facilitated by GPs to help patients to prioritise their
- 17 management goals. This will involve recognition of the adjustments and losses experienced by
- 18 patients, discussion about the non-medical elements of patients' lives and concerns and making
- 19 adequate time available within consultations, particularly for patients with complicating issues such as
- 20 depression or cognitive impairment. GPs should, and therefore trainees should be trained to,
- 21 concurrently and explicitly consider longevity and function and the compromises that managing both
- these issues may require, depending upon the context of the individual patient's values and priorities.
- 23 To support this, quality assessment of care and services, targets for care and future guideline
- 24 development and research will need to account for the impact on measurable clinical outcomes that
- 25 prioritising function over longevity may have.
- 26 The involvement of trainees in consultations is valued by patients and should be embraced by GPs
- 27 and their practices. To ensure trainees are equipped to provide effective, efficient and appropriate
- 28 care for these patients in the future, training practices need to ensure that trainees are supported to
- 29 be adequately autonomous, take adequate responsibility, integrate with the primary care team and

- 1 focus trainees' attention explicitly on the challenges and approaches to managing multimorbidity in 2 the face of uncertainty and/or discordant conditions and management recommendations. The value 3 patients see trainees as having should be made explicit to trainees to break down the fears identified 4 about not being useful and causing harm. In return, clear plans regarding follow-up and indications for 5 return should be made to patients, to overcome their uncertainties about what constitutes significant 6 symptoms and to 'invite' them back to minimise feelings of guilt or judgement about repeated 7 appointments. 8 GPs can mitigate against the negative experiences of patients and trainees, and potentially some of 9 their own challenges, through explicit discussion and exploration of the experiences of each group 10 during interactions. A good starting point may be education and discussion based on the transformation model<sup>48</sup>, which details patients' responses to receiving a diagnosis of, and living with, a 11 12 chronic illness. Empirical work is required to investigate the value of this model in the context of
- multimorbidity and its effect on individualising care, improving patient experiences and promoting
  agreed goal setting. Further, empirical work examining the interactions of patients, GPs and trainees
  in the context of multimorbidity is needed, specifically looking at the impact of open discussions about
  uncertainties and how these are managed, novel primary care service delivery models that address
  the time, continuity and accessibility issues and the importance of relational continuity. Relational
- 18 continuity may be a key element of optimal service/education delivery in its own right, however, it may
  19 be less important if holistic, planned, coherent, accessible care/education is given with appropriate

regard to consideration and negotiation of and, support to fulfil, individualised roles, priorities and

- 21 desires. The importance of relational continuity should therefore be better understood.

## **Acknowledgements**

20

22

26

27

This study was only possible due to the efforts of the realist synthesis research team whose work produced the database used to provide the data for this study. In addition to the authors, the realist synthesis team included Joanne Protheroe, Adele Higginbottom, Anne Worrell, Harrison Carter and

#### References

Eliot Rees.

- 1 (1) Boyd CM, Fortin M. Future of multimorbidity research: how should understanding of multimorbidity
- 2 inform health system design? Public Health Reviews 2010;32(2):451-474.
- 3 (2) Fortin M, Bravo G, Hudon C, Vanasse A, Lapointe L. Prevalence of multimorbidity among adults
- 4 seen in family practice. Ann Fam Med 2005 May-Jun;3(3):223-228.
- 5 (3) Fortin M, Hudon C, Bayliss EA, Soubhi H, Lapointe L. Caring for body and soul: the importance of
- 6 recognizing and managing psychological distress in persons with multimorbidity. Int J Psychiatry Med
- 7 2007;37(1):1-9.
- 8 (4) Mercer SW, Guthrie B, Furler J, Watt GC, Hart JT. Multimorbidity and the inverse care law in
- 9 primary care. BMJ 2012 Jun 19;344:e4152.
- 10 (5) France EF, Wyke S, Gunn JM, Mair FS, McLean G, Mercer SW. Multimorbidity in primary care: a
- 11 systematic review of prospective cohort studies. Br J Gen Pract 2012 Apr;62(597):e297-307.
- 12 (6) Guthrie B, Payne K, Alderson P, McMurdo ME, Mercer SW. Adapting clinical guidelines to take
- 13 account of multimorbidity. BMJ 2012 Oct 4;345:e6341.
- 14 (7) Fortin M, Lapointe L, Hudon C, Vanasse A, Ntetu AL, Maltais D. Multimorbidity and quality of life in
- 15 primary care: a systematic review. Health Qual Life Outcomes 2004 Sep 20;2:51.
- 16 (8) Gulliford M, Cowie L, Morgan M. Relational and management continuity survey in patients with
- 17 multiple long-term conditions. J Health Serv Res Policy 2011 Apr;16(2):67-74.
- 18 (9) Yardley S, Cottrell E, Protheroe J. Understanding success and failure in multimorbidity: protocol
- 19 for using realist synthesis to identify how social learning and workplace practices can be optimised.
- 20 Syst Rev 2013 Sep 25;2:87-4053-2-87.
- 21 (10) Yardley S, Cottrell E, Protheroe J. Modelling successful primary care for multimorbidity: a realist
- 22 synthesis of successes and failures in concurrent learning and practice. In submission 2014.
- 23 (11) Richardson JC. Establishing the (extra)ordinary in chronic widespread pain. Health (London)
- 24 2005 Jan;9(1):31-48.

- 1 (12) Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the
- 2 synthesis of qualitative research: ENTREQ. BMC Med Res Methodol 2012 Nov 27;12:181-2288-12-
- 3 181.
- 4 (13) Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies. California: Sage
- 5 Publications; 1988.
- 6 (14) Yardley SJ. Understanding authentic early experience in undergraduate medical education.
- 7 Keele University; 2011.
- 8 (15) Hammick M, Dornan T, Steinert Y. Conducting a best evidence systematic review. Part 1: From
- 9 idea to data coding. BEME Guide No. 13. Med Teach 2010 Jan;32(1):3-15.
- 10 (16) Wearne S, Dornan T, Teunissen PW, Skinner T. General practitioners as supervisors in
- 11 postgraduate clinical education: an integrative review. Med Educ 2012 Dec;46(12):1161-1173.
- 12 (17) Townsend A. Applying Bourdieu's theory to accounts of living with multimorbidity. Chronic Illn
- 13 2012 Jun;8(2):89-101.
- 14 (18) Luijks HD, Loeffen MJ, Lagro-Janssen AL, van Weel C, Lucassen PL, Schermer TR. GPs'
- 15 considerations in multimorbidity management: a qualitative study. Br J Gen Pract 2012
- 16 Jul;62(600):e503-10.
- 17 (19) van der Zwet J, Zwietering PJ, Teunissen PW, van der Vleuten CP, Scherpbier AJ. Workplace
- 18 learning from a socio-cultural perspective: creating developmental space during the general practice
- 19 clerkship. Adv Health Sci Educ Theory Pract 2011 Aug;16(3):359-373.
- 20 (20) Ashley P, Rhodes N, Sari-Kouzel H, Mukherjee A, Dornan T. 'They've all got to learn'. Medical
- 21 students' learning from patients in ambulatory (outpatient and general practice) consultations. Med
- 22 Teach 2009 Feb;31(2):e24-31.
- 23 (21) QSR International Pty Ltd. NVIVO. 2011.
- 24 (22) Bower P, Macdonald W, Harkness E, Gask L, Kendrick T, Valderas JM, et al. Multimorbidity,
- 25 service organization and clinical decision making in primary care: a qualitative study. Fam Pract 2011
- 26 Oct;28(5):579-587.

- 1 (23) Loffler C, Kaduszkiewicz H, Stolzenbach CO, Streich W, Fuchs A, van den Bussche H, et al.
- 2 Coping with multimorbidity in old age--a qualitative study. BMC Fam Pract 2012 May 29;13:45-2296-
- 3 13-45.
- 4 (24) Fried TR, McGraw S, Agostini JV, Tinetti ME. Views of older persons with multiple morbidities on
- 5 competing outcomes and clinical decision-making. J Am Geriatr Soc 2008 Oct;56(10):1839-1844.
- 6 (25) Bower P, Harkness E, Macdonald W, Coventry P, Bundy C, Moss-Morris R. Illness
- 7 representations in patients with multimorbid long-term conditions: qualitative study. Psychol Health
- 8 2012;27(10):1211-1226.
- 9 (26) Bayliss EA, Edwards AE, Steiner JF, Main DS. Processes of care desired by elderly patients with
- multimorbidities. Fam Pract 2008 Aug;25(4):287-293.
- 11 (27) Mishra SI, Gioia D, Childress S, Barnet B, Webster RL. Adherence to medication regimens
- 12 among low-income patients with multiple comorbid chronic conditions. Health Soc Work 2011
- 13 Nov;36(4):249-258.
- 14 (28) Smith SM, O'Kelly S, O'Dowd T. GPs' and pharmacists' experiences of managing multimorbidity:
- 15 a 'Pandora's box'. Br J Gen Pract 2010 Jul;60(576):285-294.
- 16 (29) Schuling J, Gebben H, Veehof LJ, Haaijer-Ruskamp FM. Deprescribing medication in very
- 17 elderly patients with multimorbidity: the view of Dutch GPs. A qualitative study. BMC Fam Pract 2012
- 18 Jul 9;13:56-2296-13-56.
- 19 (30) O'Brien R, Wyke S, Guthrie B, Watt G, Mercer S. An 'endless struggle': a qualitative study of
- 20 general practitioners' and practice nurses' experiences of managing multimorbidity in socio-
- 21 economically deprived areas of Scotland. Chronic Illn 2011 Mar;7(1):45-59.
- 22 (31) Russell G, Thille P, Hogg W, Lemelin J. Beyond fighting fires and chasing tails? Chronic illness
- care plans in Ontario, Canada. Ann Fam Med 2008 Mar-Apr;6(2):146-153.
- 24 (32) Morris RL, Sanders C, Kennedy AP, Rogers A. Shifting priorities in multimorbidity: a longitudinal
- qualitative study of patient's prioritization of multiple conditions. Chronic Illn 2011 Jun;7(2):147-161.

- 1 (33) Noel PH, Frueh BC, Larme AC, Pugh JA. Collaborative care needs and preferences of primary
- 2 care patients with multimorbidity. Health Expect 2005 Mar;8(1):54-63.
- 3 (34) Cornford CS, Carrington B. A qualitative study of the experiences of training in general practice:
- 4 a community of practice? Journal of Education for Teaching 2006;32(3):269-282.
- 5 (35) Sagasser MH, Kramer AW, van der Vleuten CP. How do postgraduate GP trainees regulate their
- 6 learning and what helps and hinders them? A qualitative study. BMC Med Educ 2012 Aug 6;12:67-
- 7 6920-12-67.
- 8 (36) O'Sullivan M, Martin J, Murray E. Students' perceptions of the relative advantages and
- 9 disadvantages of community-based and hospital-based teaching: a qualitative study. Med Educ 2000
- 10 Aug;34(8):648-655.
- 11 (37) Fernald DH, Staudenmaier AC, Tressler CJ, Main DS, O'Brien-Gonzales A, Barley GE. Student
- 12 perspectives on primary care preceptorships: enhancing the medical student preceptorship learning
- environment. Teach Learn Med 2001 Winter;13(1):13-20.
- 14 (38) Cowie L, Morgan M, White P, Gulliford M. Experience of continuity of care of patients with
- multiple long-term conditions in England. J Health Serv Res Policy 2009 Apr;14(2):82-87.
- 16 (39) Heath I. In praise of young doctors. BMJ 2012 BMJ Publishing Group Ltd;345:e4549.
- 17 (40) Sinnott C, Mc Hugh S, Browne J, Bradley C. GPs' perspectives on the management of patients
- 18 with multimorbidity: systematic review and synthesis of qualitative research. BMJ Open 2013 Sep.
- 19 13;3(9):e003610-2013-003610.
- 20 (41) Carlsen B, Glenton C, Pope C. Thou shalt versus thou shalt not: a meta-synthesis of GPs'
- 21 attitudes to clinical practice guidelines. Br J Gen Pract 2007 Dec;57(545):971-978.
- 22 (42) Avery T, Barber N, Ghaleb M, Franklin BD, Armstrong S, Crowe S, et al. Investigating the
- 23 prevalence and causes of prescribing errors in general practice: The PRACtICe Study. 2012.
- 24 (43) Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity
- and implications for health care, research, and medical education: a cross-sectional study. Lancet
- 26 2012 /7/7;380(9836):37-43.

- 1 (44) Noel PH, Parchman ML, Williams JW, Jr, Cornell JE, Shuko L, Zeber JE, et al. The challenges of
- 2 multimorbidity from the patient perspective. J Gen Intern Med 2007 Dec;22 Suppl 3:419-424.
- 3 (45) Fortin M, Bravo G, Hudon C, Lapointe L, Dubois MF, Almirall J. Psychological distress and
- 4 multimorbidity in primary care. Ann Fam Med 2006 Sep-Oct;4(5):417-422.
- 5 (46) Kuluski K, Gill A, Naganathan G, Upshur R, Jaakkimainen RL, Wodchis WP. A qualitative
- 6 descriptive study on the alignment of care goals between older persons with multi-morbidities, their
- 7 family physicians and informal caregivers. BMC Fam Pract 2013 Sep 8;14:133-2296-14-133.
- 8 (47) Oliver D, Foot C, Humphries R. Making our health and care systems fit for an ageing population.
- 9 2014.
- 10 (48) Jehanne Dubouloz C, King J, Ashe B, Paterson B, Chevrier J, Moldoveanu M. The process of
- 11 transformation in rehabilitation: what does it look like? International Journal of Therapy and
- 12 Rehabilitation 2010 11/01; 2014/08;17(11):604-615.

13

## 14 Figures

Figure 1: Flowchart detailing identification of papers for interpretative meta-synthesis

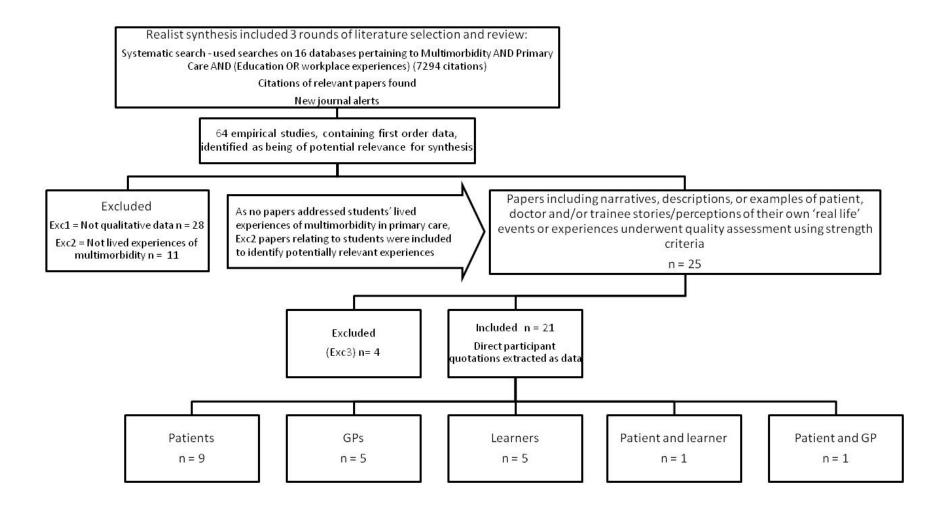
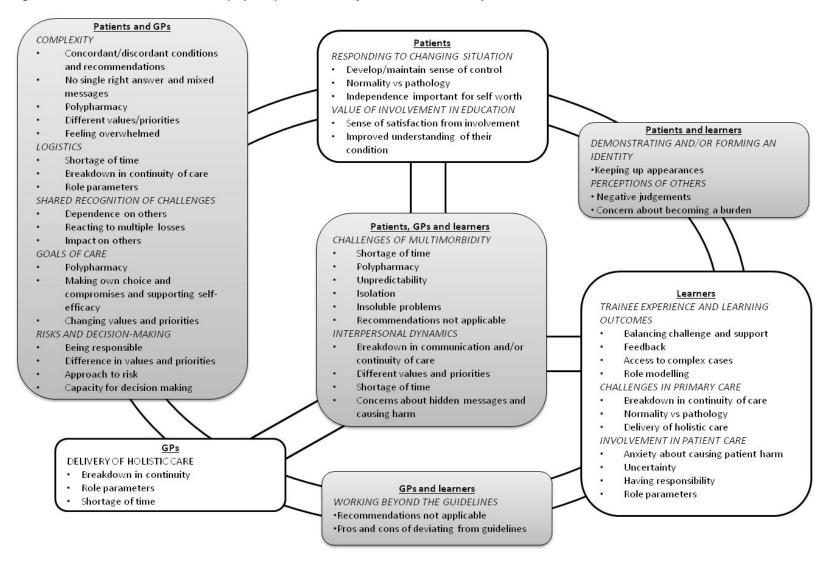


Figure 2: Initial 16 third order themes (capitals) with summary of associated concepts



# **Tables**

Table 1: Researcher derived strength score descriptors adapted for use in quality assessment for secondary analysis

Strength	Original strength score	Adapted score descriptors used for	Outcome
score	descriptors(13)	current secondary analysis	
S1	No clear conclusions can	No clear methods leading to results	Exclude paper
	be drawn. Not significant	and conclusions; not significant	
S2	Results ambiguous, but	Methods lack detail, although results	Include paper
	there appears to be a	may suggest a trend (e.g. article	
	trend	covers something unique)	
S3	Conclusions can probably	Methods appropriate for our	Include paper
	be based on the results	research question (population, data	
		generated, data presented)	
S4	Results are clear and very	Methods are very clear and very	Include and consider
	likely to be true	likely to yield important data	as key paper
S5	Results are unequivocal	Methods have produced data that	Include and consider
		are unequivocal	as key paper

Table 2: Characteristics of included studies (empirical evidence of perspectives on lived experiences relevant to multimorbidity)

First	Research question/objective	Data	Perspectives:	Country	Methodology	Focus on	Strength
author/Year*		collection	population / number of		including	interactions	score
			participants		analysis		
			[studied but not included				
			in current synthesis]				
Ashley	Find out how to optimise	Interviews (on	Trainees: n=8 year 3	UK	Grounded	Interviewed	S4
2009**(20)	learning in ambulatory	exit from	students		theory	patients and	
	consultations	teaching	Patients: n=25			students to	
		consultations)				compare	
		audio-				experiences	
		recorded and					
		analysed					
		through replay					
Bayliss 2008	To explore processes of care	Interviews	Patients: n=26 (+ 5	USA	Thematic	N/A	S4
(26)	desired by elderly patients who	audio-	spouses) multimorbid		analysis		
	have multimorbidities that may	recorded and	community dwelling				
	present competing demands	transcribed	members of not-for-				

	for patients and providers to	verbatim	profit Health				
	inform the development of		Maintenance				
	future interventions		Organisation aged 65-				
			84yr				
Bower 2011	To explore GP and nurse	Interviews	GPs: n=15 working in	UK	Framework	N/A	S3
(22)	perceptions of multimorbidity	audio-	Greater Manchester		analysis and		
	and the influence on service	recorded and	[Practice nurses: n=10]		constant		
	organisation and clinical	transcribed			comparison		
	decision making.	verbatim					
Bower 2012	To examine patients'	Interviews	Patients: n=28	UK	Framework	N/A	S3
(25)	representations of multimorbid	audio-	multimorbid adults aged		analysis and		
	long term conditions and to	recorded and	39-89yr registered with		constant		
	consider the implications for	transcribed	six general practices in		comparison		
	the measurement of illness		Greater Manchester				
	representations and their use						
	in the design and development						
	of interventions						
Cornford 2006	To investigate the problems	Interviews and	Trainees: n=32 GP	UK	Thematic	N/A	S4
(34)	encountered by registrars	focus group	registrars working in the		analysis		

	during training and asses how	(n=1) audio-	North of England		encompassing		
	trainers and practices support	recorded and			several		
	them and to investigate how	transcribed			descriptive		
	GP registrar learning				and		
	exemplifies, expands and				interpretive		
	differs from the communities of				codes		
	practice concepts described by						
	Lave and Wenger						
Cowie 2009	To examine patients'	Interviews	Patients: n=33 from	UK	Thematic	N/A	S3
(38)	experiences of continuity of	audio-	seven general practices		analysis		
	care in the context of different	recorded and	in South London (n=3				
	long term conditions and	transcribed	only single morbidity)				
	models of care and to explore	verbatim					
	implications for the future						
	organisation care of long-term						
	conditions						
Fernald 2001	To identify from a student's	Focus groups	Trainees: n=171 first,	USA	Thematic	N/A	S3
(37)	perspective important context	(n=24)	second and third-year		analysis using		
	and process issues in a	transcribed	students from The		an 'editing'		

	longitudinal preceptorship	verbatim by a	University of Colorado		style of		
		court reporter	School of Medicine		analysis (i.e.		
					no pre-existing		
					theories or		
					hypotheses)		
Fried 2008	To examine the ways in which	Focus groups	Patients: n=66 aged	USA	Thematic	N/A	S3
(24)	older persons with multiple	(n=13) audio-	65yr with multimorbidity		analysis using		
	conditions think about	recorded and			constant		
	potentially competing	transcribed			comparative		
	outcomes, in order to gain				method		
	insight into how processes to						
	elicit values regarding these						
	outcomes can be grounded in						
	the patient's perspective						
Löffler 2012	How do old aged multimorbid	Interviews	Patients: n=19 aged 65-	Germany	Constant	N/A	S3
				Germany		IN/A	33
(23)	patients cope with their	audio-	85yr		comparative		
	multiple chronic diseases?	recorded and			method from		
		transcribed			grounded		
		verbatim			theory		
		verbatim			theory		

Luijks 2012**	Explore GPs' considerations	Focus groups	GPs: n=25 working	Netherlands	Constant	N/A	S4
(18)	and main aims in the	(n=5) audio-	within 40 miles of		comparative		
	management of multimorbidity	recorded and	Nijmegen		analysis		
	and to explore factors	transcribed					
	influencing this management in	verbatim					
	daily practice.						
Mishra 2011	To investigate patient's	Focus groups	Patients: n=50 aged	USA	Template	N/A	S3
(27)	perspectives of barriers and	(n=5) audio-	40yr or older with		analysis		
	facilitators to their multiple	recorded and	multimorbidities				
	medication taking as well as	transcribed	attending appointments				
	their strategies for self-care.		at University Family				
			Medicine outpatient				
			clinic at the University of				
			Maryland, Baltimore				
			School of Medicine				
Morris 2011	To examine what influences	Interviews	Patients: n=21 from two	UK	Thematic and	N/A	S4
(32)	self-management priorities for	(longitudinal	general practices in the		narrative		
	individuals with multiple long-	1yr)	North West of England		analysis		
	term conditions and how this	transcribed but	(4 did not reach end of				

	changes over time	method of	study)				
		recording data					
		not given					
Noel 2005	To explore the collaborative	Focus groups	Patients: n=60 (48 male)	USA	Thematic	N/A	S3
(33)	care needs and preferences in	audio-	in their 30s-80s with		analysis		
	primary care patients with	recorded and	multimorbidity selected				
	multiple chronic illnesses	transcribed	from Veterans Health				
		verbatim	administration from eight				
			clinics in four				
			geographical regions of				
			the USA				
O'Brien 2011	To understand GPs' and	Interviews	GPs: n=15 GPs in four	UK	Constant	N/A	S4
(30)	practice nurses' experiences of	audio-	practices in deprived		comparative		
	managing multimorbidity in	recorded and	areas of Glasgow		analysis		
	deprived areas and elicit views	transcribed	[Practice nurses: n=4]				
	on what might help	verbatim					
O'Sullivan	To obtain the perceptions of	Interviews and	Trainees: n=42 (n=24	UK	Thematic	N/A	S2
2000 (36)	first year clinical medical	focus groups	interviews, n=18 focus		analysis using		
	students of the relative	(n=3) audio-	groups) from University		grounded		

	advantages and	recorded and	College London Medical		theory		
	disadvantages of community-	transcribed	School				
	based and hospital based						
	clinical teaching;						
Russell 2008	To investigate the experience	Interviews	Patients: n=20 aged 50-	Canada	Constant	Both patients	S3
(31)	of family physicians and	(post RCT)	90 years (n=3 had		comparative	and GPs	
	patients with a chronic illness	audio-	spouse or child present)		analysis	interviewed but	
	management initiative that	recorded and	GPs: n=13			no explicit focus	
	involved the joint formulation of	transcribed	[Study facilitators: n=3]			on interactions	
	comprehensive individual	verbatim, field	From the Ottawa and			described	
	patient care plans	notes and	Hamilton/Wentworth				
		facilitator	areas of Ontario				
		narratives also					
		recorded					
Sagasser	To explore how postgraduate	Interviews	Trainees: n=21 first and	Netherlands	Thematic	N/A	S4
2012 (35)	trainees regulate their learning	audio-	third-year GP trainees		analysis		
	in the workplace, how external	recorded and	from the universities of				
	regulation promotes self-	transcribed	Nijmegen and				
	regulation and which elements		Maastricht				

	facilitate or impede self-						
	regulation and learning.						
Schuling 2012	Too explore how experienced	Focus groups	GPs: n=29 with a	Netherlands	Thematic	N/A	S3
(29)	GPs feel about deprescribing	(n=3) audio-	minimum of 5 years		analysis		
	medication in older patients	recorded and	experience and active				
	with multimorbidity and to what	transcribed	GP Trainers				
	extent they involve patients in	verbatim					
	these decisions.						
Smith 2010	Explore the views and	Focus groups	GPs: n=13 tutors for	Ireland	Framework	N/A	S3
(28)	attitudes of GPs and	(n=2 GP, n=1	undergraduate medical		analysis		
	pharmacists managing	pharmacists)	students at Trinity				
	patients with multimorbidity in	audio-	College Dublin				
	primary care	recorded and	[Pharmacists: n=7]				
		transcribed					
Townsend	Advance understandings of the	Interviews (two	Patients: n=8 in their	UK	Grounded	Methods	S4
2012** (17)	lived experience of	interviews	early 50s, who had four		theory	designed to look	
	multimorbidity in broader	three weeks	or more chronic			at patients'	
	cultural and structural settings	apart) audio-	illnesses and high			experiences of	
		recorded and	consulting rates			patient-doctor	

		transcribed	selected from a			interactions	
		verbatim	longitudinal community				
			health survey in the				
			West of Scotland				
Van der Zwet	To clarify how medical	Focus groups	Trainees: n=44 year 5	Netherlands	Thematic	'questions	S4
2010** (19)	students learn by participating	(n=7) audio-	students at Maastricht		analysis	were asked	
	in general practice and the role	recorded and	University in week 8-9 of		leading to a	about the nature	
	of the socio-cultural context	transcribed	a 10 week general		conceptual	of the students'	
	therein	verbatim	practice clerkship		model	participation,	
						their position	
						and role in the	
						practice and	
						how these	
						elements	
						influenced their	
						learning	
						experiences.'	

<sup>\*</sup>See list of citations for full references of papers included in the review

\*\*Key papers (see figure 1 for details)