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Living with multimorbidity? The lived experience of multiple chronic conditions in later life

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Abstract:	<p>Multimorbidity is defined biomedically as the co-existence of two or more long-term conditions in an individual. Globally the number of people living with multiple conditions is increasing, posing stark challenges both to the clinical management of patients and the organisation of health systems. Qualitative literature has begun to address how concurrency affects the self-management of chronic conditions, and the concept of illness prioritisation predominates. In this paper, we adopt a phenomenological lens to show how older people with multiple conditions experience illness. This UK study was qualitative and longitudinal in design. Sampling was purposive and drew upon an existing cohort study. In total 15 older people living with multiple conditions took part in 27 in-depth interviews. The practical stages of analysis were guided by Constructivist Grounded Theory (Charmaz 2006). We argue that the concept of multimorbidity as clinically imagined has limited relevance to lived experience, whilst concurrency may also be erroneous. In response, we outline a lived-experience of multiple chronic conditions in later life, which highlights differences between clinical and lay assumptions and makes the latter visible.</p>

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Living with multimorbidity? **The lived experience** of multiple chronic conditions in later life

Abstract

Multimorbidity is defined biomedically as the co-existence of two or more long-term conditions in an individual. Globally the number of people living with multiple conditions is increasing, posing stark challenges both to the clinical management of patients and the organisation of health systems.

Qualitative literature has begun to address how concurrency affects the self-management of chronic conditions, and the concept of illness prioritisation predominates. In this paper, we adopt a

phenomenological lens to show how older people with multiple conditions experience illness. This UK study was qualitative and longitudinal in design. Sampling was purposive and drew upon an existing cohort study. In total 15 older people living with multiple conditions took part in 27 in-depth interviews. **The practical stages of analysis were guided by Constructivist Grounded Theory (Charmaz**

2006). We argue that the concept of multimorbidity as clinically imagined has limited relevance to lived experience, whilst concurrency may also be erroneous. In response, we outline a **lived-**

experience of multiple chronic conditions in later life, which highlights differences between clinical and lay assumptions and makes the latter visible.

Abstract: 177 words

Main text: 7993 words

Multimorbidity represents a fundamental challenge to established modes of health organisation and care. This paper addresses the lived experience of multiple chronic conditions and details how this perspective diverges from the biomedical conception of multimorbidity. The phenomenologically **informed** outline of multiple conditions we present provides a model to counterpoise the clinical conception of multimorbidity wherever it prevails.

Background

Multimorbidity is defined biomedically as the 'co-existence of two or more long-term conditions in an individual' (Mercer et al., 2009). Epidemiological research estimates the prevalence of multimorbidity among older people to be as high as 66.2% (Glynn et al., 2011) and in primary care multiple diagnoses are said to be the rule rather than the exception (Fortin et al., 2005).

Multimorbidity is a global health challenge not limited to high income countries (Afshar et al., 2017). Clinical research has shown that having multiple conditions is associated with adverse individual outcomes, including increased mortality rates (Wei and Mukamal, 2017), poorer health related quality of life (Tyack et al. 2018) and reduced physical functioning (Ryan et al., 2015). Health economic research has also shown that multimorbidity results in higher costs across health and social care (Wang et al. 2017).

Alongside epidemiological and economic research, a burgeoning qualitative literature now addresses the lived experience of multiple conditions with a focus on self-management. A significant early contribution made by Bayliss et al. (2003) reported that a single 'dominant condition' often impedes the self-care of other conditions (Bayliss et al., 2003: 19), yet this same study was unable to discern any pattern according to which conditions predominate. Subsequent qualitative studies have sought to identify the seemingly elusive patterning of 'illness prioritisation' within multimorbidity. Some present illness prioritisation as a 'strategic choice' whereby ill people marshal resources towards the self-care of particular conditions. Multimorbidity, it is suggested, involves 'prioritising a main health condition', which demands that people 'choose to respond to one health condition over another' (White, Lentin and Farnworth, 2016: 94). Factors affecting such choices include perceptions of condition severity (Schoenberg et al. 2009), the efficacy of medication and the risk of associated diseases (Elliot et al. 2007). However, further studies report that people living with the same combination of conditions often understand illness in different ways (Lindsay 2009; Mc Sharry et al. 2013) seemingly confounding the idea that multimorbidity can be reduced to a set of distinguishable

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2
3 disease entities. Morris et al. (2011) present prioritisation as a dynamic, yet deliberative process,
4
5 wherein the priorities of people living with multiple conditions shift according to the 'timing
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7 between diagnoses, prior experiences, recommended self-management activities, bereavement,
8
9 contact with health services and flare-up of conditions' (Morris et al., 2011: 153). Cheraghi-Sohi et al.
10
11 (2013) argue that social context, clinical interactions, and the ability to control symptoms also shape
12
13 the way lay people prioritise different conditions and symptoms. Others suggest that this complexity
14
15 means self-management is unrealistic for people with multiple conditions and that alternative
16
17 palliative models are more appropriate (Francis, Carryer and Wilkinson 2018).
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21
22 A small number of qualitative studies question key epistemic assumptions in clinical, epidemiological
23
24 and health economic readings of illness. Accordingly, self-management only partially explains the
25
26 lived experience of multiple conditions, which is defined in large part by the efforts to preserve
27
28 selfhood (Townsend et al. 2006) and morally valued bodies (Hurd Clarke and Bennett 2012). Pickard
29
30 and Rogers (2012) further critique the epistemological basis of self-management, arguing instead for
31
32 the recognition of embodied knowledge – a form of lay knowledge at odds with the 'abstract,
33
34 rational model of patient knowledge assumed in programmes like the EPP [Expert Patient
35
36 Programme]' (Pickard and Rogers, 2012: 16). These studies sit within a broader sociological
37
38 tradition, which challenges biomedical readings of the body and behaviour (Cohn 2014), and point
39
40 instead to role of embodied, biographical and social factors in framing the meaning of illness
41
42 (Williams 2000).
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46
47 Qualitative meta-syntheses of multimorbidity research reflect, and reinforce, the broader corpus.
48
49 Bratzke et al. (2015) state that multimorbidity is marked by 'competing demands' and that people
50
51 with multiple chronic conditions 'select and order their self-management behaviours', managing one
52
53 disease at the expense of others (Bratzke et al. 2015: 753). Another synthesis depicts multimorbidity
54
55 as a 'state of complexity' wherein conditions are 'strategically self-managed by marshalling medical
56
57 and behavioural resources to preserve self-identity' (Coventry et al. 2015: 8). However, recent
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3 quantitative research has shown that people living with multiple conditions identify different
4 conditions as burdensome, suggesting that the relationship between medical diagnoses and illness
5 experience is complex (Slightam et al. 2018).
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10 The purpose of this study was to understand how older people living with multiple chronic
11 conditions make sense of illness. Our aim is to provide a foundational reading of multiple chronic
12 conditions, beginning with the premise that medical diagnoses do not *a priori* determine illness. This
13 argument extends from immediate embodied experience to include the social and cultural schemes
14 through which illness gains meaning. Our findings hold implications for the conceptualisation of
15 multimorbidity and thus for healthcare organisation, delivery and education where the concept
16 prevails.
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26 27 **Theoretical perspective** 28

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30 **We begin** by recognising the primacy of embodiment and adopt a lived body perspective. This
31 perspective derives from phenomenological readings of the body, juxtaposed to archetypal
32 biomedical images of the body as mechanistic and amenable to observation, intervention and
33 control. Prototypically outlined by Merleau-Ponty, the lived body perspective understands the body
34 not simply as a thing-in-the-world, but as the 'medium for having a world' (Merleau-Ponty 2003:
35 169). The body is a medium in our sense-making practices because, unlike inanimate objects, it is
36 intentional and directed towards an experiencing world. Through this intentionality both the body,
37 and the world, become meaningful. As Leder states: 'we cannot understand the meaning and form
38 of objects without reference to the bodily powers through which we engage them – our senses,
39 motility, language, desires. The lived body is not just one thing *in* the world, but a way in which the
40 world comes to be' (Leder 1990: 123).
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55 A second tenet of our analysis is that the body, in the absence of illness, is characterised by
56 effacement. Leder (1990) outlines a phenomenology of the 'normal' body as characterised by three
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3 forms of bodily disappearance: *focal disappearance* whereby organs disappear from perception
4 when they form the focal origin of our perceptual field, *background disappearance* whereby bodily
5 regions disappear into a general 'corporal gestalt' (Leder 1990: 26), and *depth disappearance*
6 whereby visceral organs and vital functions recede from awareness because they do not directly
7 perceive or act upon the world (Leder 1990: 53). When we become ill or experience pain, our
8 perceptual schemes transform, and that which was once invisible becomes visible; bodies become
9 'opaque' as they enter into subjectivity as an alien presence (Leder 1990: 82). The body and its
10 visceral processes become apparent through their dysfunction, a shift Leder coins dys-appearance.
11
12 Once apparent, pain and illness make a twofold 'telic demand' upon the subject for hermeneutic and
13 pragmatic action (Leder 1990; 78). Hermeneutic action calls for the subject to make sense of
14 impairment, whilst the pragmatic moment compels control over the body. These demands open the
15 lived body onto myriad socio-cultural schemes of meaning, as well as social and material
16 opportunities and constraints for action. It is acted upon through intersubjective and material
17 interactions, and is interpreted through cultural schemes inscribed by relations of power – the body
18 becomes gendered (Young 1980), racialized (Lee 2014), aged (Gilleard and Higgs 2014) and
19 oppressed (Hughes and Paterson 1997). Embodiment thus conceived involves a subject-object
20 dialectic whereby the body is simultaneously perceiver and perceived, and neither the body, nor the
21 world it inhabits, may be understood without this relation.
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45 This paper adopts a lived body perspective to delineate lived experiences of multiple conditions, and
46 to highlight interactional and interpretive schemes that give meaning to the dys-appearing body.
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50 **Methods and data collection**

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53 The data presented in this paper are taken from the lead author's UK based doctoral research.
54
55 Ethical approval was attained from the regional National Health Service Research Ethics Committee.
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3 Principal study participants (those with multiple conditions) were purposively sampled and recruited
4
5 from an existing cohort study, the XX study (XX). The XX study sample contained older adults with
6
7 clinical diagnoses of osteoarthritis (OA) and cardiovascular disease (CVD), including hypertension,
8
9 heart disease, and heart failure. The current study recruited from a subgroup of XX participants who
10
11 consented to further contact. These participants had a historic diagnosis of OA and CVD, however all
12
13 reported additional chronic and episodic conditions during interviews (outlined in Table 1).
14
15

16 Participants were invited to participate by post and responded using pre-paid forms. Four participant
17
18 spouses (secondary study participants) were recruited to provide data on social support (a distinct
19
20 theme within the doctoral research) but this data does not feature in the current paper.
21
22

23
24 Principal participants took part in up to two in-depth qualitative interviews spaced three to six
25
26 months apart. This design allowed for greater rapport between participant and interviewer, whilst
27
28 also allowing for longitudinal changes in participant's circumstances to be recorded. Interviews were
29
30 conducted by the lead author (between 2013 and 2014) in participant's homes, lasted between 45
31
32 and 90 minutes, and followed a topic guide that was iteratively refined throughout data collection.
33
34 The data generated were in-depth and the each interview typically covered each participant's
35
36 history of illness, the meaning of illness and the body. Prior to interviews, participants were given
37
38 study information sheets in accessible formats. All participants provided informed consent prior to
39
40 interviews and this was reaffirmed after each interview. Interviews were transcribed verbatim, with
41
42 all personally identifying information removed. Data storage and administration were conducted
43
44 using QSR Nvivo 10 on password protected servers.
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49 The sample consisted of eight female and seven male participants; three female spouses and one
50
51 male spouse were also recruited. Participants were aged 59-84. Five participants lived alone, ten
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53 cohabited. Seven participants were single, eight were married. The sample was ethnically and
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55 culturally homogenous; fourteen participants were white British, one participant was white non-
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3 British. The employment status of the sample was also homogenous; thirteen participants were
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5 retired, one worked full-time, one worked part-time.
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8 The ontological framing of this paper assumes that the experience of one's body is a combination of
9
10 both sense-data and the interpretation of this data through socio-cultural schemes. Our aim is to
11
12 present an account of the lived body as it is socially produced, rather than to identify essential
13
14 psychological structures. Therefore, whilst we draw upon phenomenological theory in the
15
16 conceptualisation of our data, we do not employ an explicit phenomenological method. Instead we
17
18 proceed from a more general interpretive standpoint, which recognises the role of the researcher in
19
20 the production of knowledge, and the practical stages of data analysis are drawn from Constructivist
21
22 Grounded Theory (Charmaz 2006). The first stage of coding was 'initial coding' using line-by-line
23
24 coding. Following initial coding, increasingly directed and conceptually driven 'focused coding' was
25
26 undertaken. Focused coding involved identifying and expanding the most theoretically significant
27
28 and frequently occurring codes delivered through initial coding. A final stage of 'theoretical coding'
29
30 addressed categories of codes generated through focused coding. In practice, our analysis delivered
31
32 a 'theory' or conceptualisation with extensive parallels to existing phenomenological literature and it
33
34 was during theoretical coding that Leder's (1990) 'dys-appearing body' was drawn upon, as a means
35
36 of bringing coherent form and clarity to our concepts and as a tool to 'weave the fractured story
37
38 back together' (Glaser 1992: 71). Coding was conducted by the lead author and each coding stage
39
40 was subject to review by co-authors. This involved independent coding of data by co-authors, who
41
42 then interrogated the codes developed by the lead author.
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49 The study did not raise any particular ethical concerns, apart from asking participants to discuss
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51 potentially upsetting topics. These discussions were conducted so that participants retained control;
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53 the interviewer took care to remind participants they could pause or stop the interview at any time.
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Findings

Data show that the clinical definition of multimorbidity – the co-occurrence of two or more chronic conditions in an individual – fails to capture the lived experience. Participants questioned the significance and meaning of clinically diagnosed conditions, and for some, the label of concurrence was erroneous. Participants made sense of illness using clear interpretive schemes, which we term lay logics of meaning. These logics pertain to individualised notions of embodied normality, and the intersecting motifs of control, biography, ageing, and biomedicine. We first introduce data problematizing the biomedical construction of multimorbidity, then show how participants made sense of illness and their bodies through different logics of meaning.

Living with multimorbidity?

To presume multimorbidity is experienced as the co-occurrence of two or more chronic conditions masks two basic assumptions. First, that people understand their health and illness according to clinically diagnosed conditions; and second, that these conditions are experienced as phenomenologically concurrent. Participant data challenge these assumptions, and show the lived experience of multiple conditions to be more complex than a count of clinical diagnoses alone:

I've got the diabetes, I've got the blood pressure, I've got arthritis in my knees, fair enough, but to me I'm not ill. It's just an inconvenience. It's like if you break your arm, you've got one arm in a bloody sling, you've only got one arm to work with. You're not ill, are you? [Rhetorical].

(ID:109.)

Despite living with a number of clinically diagnosed conditions, this participant rejects the label of illness as a characterisation of his experience. Instead, he frames medical complaints as an 'inconvenience' because he understands illness not simply as the presence of disease, but the extent to which impairment affects his everyday life. When our interviewer asked this participant to expand upon his understanding of illness, he replied in clear terms:

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3 *If I was ill I'd be in pain... stomach, chest, the bits that matter in the middle. That's being ill to*
4 *me. You've got no control over it... Appendicitis or if you've got bloody transplants, that's being*
5 *ill... [Whereas] If you break your arm, you're not ill. It's a bloody inconvenience. It's like my*
6 *knees, they're an inconvenience, but it's something you've got to put up with. (ID: 109.)*
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13 Impairment transforms the meaning of the material environment and thus the body. However in this
14 case the transformation is relatively minor, an inconvenience, rather than an experience dominated
15 by disability. Our participant has a clear understanding of what it means to be an 'ill person'. Illness
16 means losing control, diseased visceral organs, or complex clinical interventions. In the absence of
17 these signs or symptoms, this participant, despite multiple diagnoses, understands his health as the
18 practical limitations impairment confers.
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27 Another participant, a woman living with systemic lupus, OA, depression, and an addiction to opioid
28 medication, expressed similar reasoning. This participant was a nurse by profession and recognised
29 the importance of multimorbidity to clinical practice. Despite this, when describing her own
30 experience of illness, she questioned the relevance of multimorbidity as clinically imagined:
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37 *I don't look at myself as this ill person with all these things going on. Even on the worst day, it*
38 *was always because it was one particular thing that was the problem at the time. So anything*
39 *else associated or not associated with that didn't really come into... if it was arthritis that was*
40 *the problem, then that was the problem. (ID: 112.)*
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47 This participant questions the label of illness and problematises the notion of concurrency.

48 Concurrency, as generally imagined within epidemiological literature (Valderas et al. 2009), assumes
49 the synchronous presence of multiple conditions. Yet as this participant explains, the lived
50 experience of concurrence is characterised by fluctuating symptoms, meaning that a single symptom
51 or condition may dominate experience at any one time. Redolent of Leder's (1990) dys-appearing
52 body, symptoms and conditions slip in and out of apprehension according to their perception. Thus,
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3 we can say that whilst concurrence is a defining feature of multimorbidity as an object of biomedical
4 knowledge, concurrence does not define this participant's experience of multiple conditions.
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7
8 Several participants made reference to 'borderline' conditions when describing their health, and
9 where this occurred, the ambiguity between embodied experiences and clinical diagnoses
10 problematized concurrence further. The following quotations, both from female participants, are
11 exemplary:
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18 *I had a diabetic foot in October and nearly lost my toe; it went black. I'm borderline diabetes;*
19 *I'm not classed as a diabetic. (ID: 101.)*
20
21

22
23 *My blood pressure has fallen again but only, probably just in the zone he [consultant] wanted*
24 *which was... was it 70 over? No 100 over – I can't remember. Something over 70... he said,*
25 *"Well, it's borderline". (ID: 104.)*
26
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30
31 The 'borderline' status of diabetes and hypertension means these conditions are experienced as
32 simultaneously present and absent. Illness is present insofar as both participants have an awareness
33 of risk, which may require preventative or remedial action. At the same time the 'borderline' status
34 denotes illness as absent – as the first participant explains, 'I'm not classed as a diabetic'. These
35 excerpts highlight the importance of inchoate aspects of ill health (Scott et al. 2005) as the latent
36 possibility of illness shapes how both women understand their bodies and the meaning of their
37 health.
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48 Other participants spoke about illness in ways that highlight a more general dissonance between
49 diagnosed conditions and the lived experience of multimorbidity.
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53 *I have a chest problem which just flares up now and again, but I've had that for a lot of years.*
54 *It's not chronic, but it's just that sometimes I wheeze quite a lot and other times it's okay. I had*
55 *bronchitis a long time ago. I had to go to the chest clinic... The only diagnosis they could come*
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3 *up with was bronchitis. It wasn't a permanent thing. Even in this warm weather, people would*
4
5 *say to me, 'Have you got a bad cold?' I haven't, it's just the rustiness in my throat. (ID: 111.)*
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9 This participant's 'chest problem' was among her most salient concerns, yet in the absence of a
10
11 clear clinical explanation its meaning remains ambiguous. One explanation may be that her
12
13 'weakness' is a sign of chronic bronchitis, but she understands this issue differently. This
14
15 complaint gains significance only when our participant perceives it as a physical impairment, or
16
17 when others recognise it during interactions. Once perceived, lay terminology of 'weakness' and
18
19 'rustiness' help bring sense to her symptoms.
20
21

22 23 **Lay logics of meaning**

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26 Lived experience diverges from clinical definition, but lay perspectives are not irrational and
27
28 participants revealed clear interpretive schemes when making sense of illness. Recalling Leder's
29
30 (1990) 'twofold telic demand' for hermeneutic and pragmatic action, we outline how the motifs of
31
32 control, biography, ageing and biomedicine relate to participants' perceptions of, and efforts
33
34 towards, embodied normality.
35
36

37 38 *Normality and control*

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40
41 Chronic illness is often marked by a perceptual shift, as life veers from a once 'normal trajectory'
42
43 towards one that feels 'fundamentally abnormal and inwardly damaging' (Bury 1982: 171). Notions
44
45 of normality, of life before illness, are powerful reference points. Normality may be a goal, a
46
47 yardstick against which progress is measured, or a painful reminder of what has been lost. For
48
49 participants in this study, efforts to 'carry on as normal', to maintain social relationships and
50
51 continue in valued activities were common. For many, illness became meaningful as symptoms or
52
53 physical limitations punctured some aspect of normality.
54
55

56
57
58 *It's there, these things... one, two or three, whatever you've got, arthritis, asthma, you've just*
59
60 *got to live with it. It's there and until I start coughing, you just carry on as normal. Just carrying*

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3 *on until you try to do something, getting stuff out of a cupboard or something, then you realise*
4
5 *that you've got that condition. (ID: 102.)*
6
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8 This excerpt illustrates how individual conceptions of normality act as a foundation upon which
9
10 illness gains meaning. Our participant describes being able to 'carry on as normal' despite living with
11
12 multiple conditions, and it is only when some aspect of daily life becomes impeded that illness is
13
14 comprehended. When normality is impinged it is those disrupting features of illness are propelled to
15
16 the foreground of experience.
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19
20 Another male participant shed further light on the link between disrupted normality and the
21
22 meaning of multiple conditions:
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26 *I'm living with these aches and pains, as it were, you know? But quite often, while this*
27
28 *weather's been on, I've started coughing when I'm in bed and I've had to get up. I may have*
29
30 *gone to bed about 10 or 12 o'clock, and I've had to get up because I'm coughing that much...*
31
32 *The night's worse with this with asthma, it's so long if you are coughing during the night.... It's*
33
34 *a long time till breakfast. (ID: 103.)*
35
36

37
38 Our participant says that the 'aches and pains' associated with OA are not so onerous as to prevent
39
40 normality, whilst sleepless nights caused by episodes of coughing are more disruptive. This is
41
42 understandable given that sleep is a socially organised practice, which gives meaning and order to
43
44 our social worlds (Williams 2002). The disruption of sleep means the disruption of normal life, of
45
46 typical patterns of interactions and activities. The statement 'It's a long time till breakfast' conveys
47
48 the isolation and suffering that mark these experiences, and explains why asthma and cough
49
50 dominate this participant's experience of illness.
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54 Control engenders normality and participants spoke about control as the means of attaining
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56 embodied normality, as the motivation for self-management activities, and shaping the meaning of
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3 illness in prospective terms. For many, medication was the primary means of recovering control over
4
5 illness and the body.
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9 *As long as the medication is controlling the blood pressure, I should be fine. As long as I take the*
10
11 *eye drops – I can't focus with one eye, I have a problem with one eye, and that's been the*
12
13 *situation since I was a child really. I've basically only got one good eye. If I was to lose that, then I*
14
15 *would have serious issues, but I'm told that as long as I continue taking the drops; as long as I*
16
17 *attend the eye clinic regularly, for them to check the eye pressures, then hopefully, everything's*
18
19 *under control. (ID: 102.)*
20
21

22
23 This participant's feelings of control over future complications shape the meaning of hypertension
24
25 and glaucoma. He understands clearly the risks posed by hypertension, whilst his reference to
26
27 having only 'one good eye' crystallises the threat of glaucoma. Yet medication has delivered a sense
28
29 of control, and as the perceived risks posed by both conditions abate, so too, in our participant's
30
31 view, does their significance.
32
33

34
35 In another example, a male participant explained that his ability to control diabetes had curtailed the
36
37 significance of this condition. This participant received a diagnosis of type 2 diabetes shortly before
38
39 his first interview, at which point it was a major concern. However, by the time of his follow-up
40
41 interview (4 months later), he spoke impassively about this diagnosis:
42
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44

45
46 *I'm keeping it under control. I think I am, anyway. I've got to go back August, for another blood*
47
48 *test and check-up. If it stays as it is, or comes down again, I shall be quite happy. (ID: 109.)*
49
50

51 Dietary changes and medication have enabled control and allayed the threat posed by this condition
52
53 to health, the body and everyday life. With control, the significance of diabetes diminishes and our
54
55 participant appears untroubled by this diagnoses.
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3 The importance of control was underscored where participants spoke of being unable to control
4
5 illness and the body. One participant described his experiences following radical prostatectomy and
6
7 his struggle to come to terms with incontinence:
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9

10
11 *I'm 18 months on and I've still got a nappy on, which sickens me at times it really does. You're*
12
13 *going out and you think, "Bloody hell, I'd better go and have a wash and change that" because*
14
15 *you think you can smell yourself. It's not very nice. (ID: 107.)*
16
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18
19 This case illustrates clearly the link between control and normality, and shows how a lack of bodily
20
21 control can frustrate efforts to regain normality. Incontinence is experienced as an acute lack of
22
23 control, both physically and emotionally, as shame and embarrassment threaten to undermine this
24
25 participant's sense of self. Incontinence and its associated stigma anchor this participant's life in
26
27 illness; 18 months after surgery, his distress at the lack of normality is palpable.
28
29

30 31 *Biography and normality*

32
33 The lens of normality, which confers meaning on illness, is shaped in turn by individual biography.
34
35 Chronic illness may be experienced as a sudden crisis during which biography is disrupted (Bury
36
37 1982) or it may be an anticipated feature of one's social and temporal milieu (Fairclough et al. 2004).
38
39 Multiple diagnoses were a recent development for some participants, whilst others had lived with
40
41 illness and impairment since childhood. Our data show that the way this multiplicity is understood
42
43 (both as individuated conditions and also as gestalt) varies according to biographical context.
44
45
46

47
48 When asked to describe his overall health, one male participant listed OA, heart disease, and
49
50 hypertension. Prompted to give a fuller picture of his health, this participant proceeded to identify
51
52 another health concern:
53
54

55
56 *My other main problem would be as a teenager I suffered from osteomyelitis, which meant*
57
58 *that I was operated on my right ankle. They removed diseased bone. I was in plaster for 12*
59
60

1
2
3 *months. And now as I've got older it's turned arthritic. So the ankle ... when I exercise it*
4
5 *stiffens. If I rest it up, when I wake up of a morning, it's stiff. So, I'm limping around for a good*
6
7 *couple of hours. (ID: 102.)*
8
9

10
11 Biographical context frames the meaning of this impairment, its aetiology, and the impact it has
12
13 on this participant's life. This impairment is not biographically disruptive (although it likely was as
14
15 a teenager) because over many years the limitations it confers have been incorporated into a
16
17 stable sense of embodied selfhood. Our participant regards this aspect of ill-health to be normal:
18
19 'It's painful, it's stiff, it aches, but you learn to live with it'. Consequently, the significance of this
20
21 painful and limiting impairment is diminished, and when asked 'on a day-to-day basis, what are
22
23 you most aware of?' this participant replied 'the blood pressure, obviously, because I'm taking
24
25 medication on a daily basis'. Pain and stiffness pose little threat to this participant's embodied
26
27 self because these complaints are a consistent feature of a coherent biography and are not
28
29 considered dysfunctions. In contrast, hypertensive medication acts as a daily reminder and mean
30
31 this condition, whilst asymptomatic, is more readily perceived.
32
33
34
35

36
37 Another male participant expressed similar reasoning when talking about his congenital foot
38
39 deformity:

40
41
42 ID: 108: *The doctor offered me some painkillers and I said 'No thank you'... I don't want*
43
44 *something that is another addictive thing. Every time you have a pain you take a*
45
46 *painkiller. With my foot, I'm not being funny now, I'm not looking for sympathy, but I*
47
48 *have pain with it all the time. Not now, but when I start walking, I can only walk so*
49
50 *far before it aches. But that is nothing to do with my health. That's just the way it*
51
52 *was born.*
53

54
55
56 Int: *So you don't consider that a health problem?*
57

58
59 ID 108: *No, because I've had that from birth.*
60

1
2
3 Impairment is so closely enmeshed with this participant's biography that he does not consider pain
4 and functional limitations to be health problems. He rejects the pathological lens, and instead
5
6 regards impairment as a normal bodily state, leading him to eschew medical intervention.
7
8
9

10 *Age and normality*

11
12
13
14 Biography and notions of normality are structured by the individual's position in the life course. The
15
16 'social clock' of illness explains how age-related cultural referents shape expectations of health and
17
18 illness within a biographical context (Bury and Holme 1991) and previous studies have shown how
19
20 the 'social clock' mediates the meaning to conditions and events such as arthritis and strokes in later
21
22 life (Sanders 2002; Faircloth 2004). In this study of multiple chronic conditions, participants drew on
23
24 the imagery of ageing both at the general level of multiple conditions, and also the specific level of
25
26 symptoms and conditions within that multiplicity.
27
28

29
30 At the general level, several participants invoked age when reflecting upon the accumulation of
31
32 multiple health concerns. One male participant said:

33
34
35
36 *I just think that it's part of life's rich tapestry, to be honest with you. That it's inevitable that*
37
38 *with age you're going to have... you're going have issues. (ID: 109.)*
39
40

41 This participant understands the accrual of health problems to be a normal part of the ageing
42
43 process. One consequence of this, it is reasonable to assume, is that the multiplicity of conditions
44
45 is in itself unlikely to threaten his sense of self or anticipated future as it might were he younger.

46
47 A female participant expressed similar views when talking about recent reductions in her
48
49 mobility:
50

51
52
53 *I think that the last 12 months perhaps it has gone, deteriorated a little more. But all I can say*
54
55 *is that it's something I have to accept. Of course, my own body as well, my age doesn't help*
56
57 *because you're obviously not agile anymore. But as I say, I'm grateful that I am where I am.*
58
59 (ID: 111.)
60

1
2
3 At the same time, participants also associated specific conditions with later life:
4
5

6 *I have osteoarthritis in my back, which I take medication for. But I mean, you have it in your*
7 *fingers and that, but that's a natural thing that comes with your age. (ID: 111.)*
8
9

10
11 The association between arthritis and ageing was common (so too was the link between
12 hypertension and later life) and we concur with previous studies that recognise the role of culturally
13 constituted links between ageing, illness, and physical decline in giving meaning to the experience of
14 illness (Sanders 2002; Faircloth 2004). However, whilst participants identified certain conditions as a
15 normal feature of later life, other concurrent conditions were not. Cancer, for example, was not
16 described as normal, 'natural', or an inevitable feature of ageing. We can say, therefore, that the
17 'social clock' of illness shapes meaning at the general level of accumulated health complaints, but
18 varies according to specific conditions within that multiplicity.
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30 *Biomedicine and health professionals*

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33 Biomedicine and interactions with health professionals provide a further interpretive scheme.

34 Several participants spoke about risk factors, clinical prognoses, and pathophysiological associations
35 when making sense of their health. One male participant drew upon such concepts when explaining
36 the meaning of cancer and hypertension:
37
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39
40
41

42 *Cancer is the one that preys on you, really... because they can sneak back anytime. So as long*
43 *as I can keep that in, I can manage. Because, the other week when I went for my annual check-*
44 *up with my GP, my blood pressure was 135/74, which is pretty good. He said everything's all*
45 *right there, so that's under control. (ID: 107.)*
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52
53 This participant deploys basic biomedical knowledge to make sense of illness. He presents cancer
54 and hypertension within a hierarchy of risk, in which cancer supersedes hypertension due to the
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3 risk of reoccurrence and mortality. Hypertension is also framed biomedically through the
4 reporting of blood pressure readings, which appear to afford this participant a sense of control.
5
6

7
8 Risk factors were widely referenced by participants, and hypertension in particular became
9 meaningful through its association with cardiovascular events. One female participant said that
10 hypertension was not 'on her radar' because it was controlled by medication. However, when asked
11 how she would feel if her blood pressure were to rise, she replied 'I'd be thinking strokes, heart
12 attack' (ID: 112). Another female participant said:
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21 *I wouldn't say that I think about it [hypertension], but if you don't feel well, or sometimes you'll*
22 *get up and you'll not feel on top hole, you do think about it, because something that you worry*
23 *about more than anything at this age is strokes. Of course, with blood pressure, you do think*
24 *about it a bit like that. (ID: 111.)*
25
26
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30
31 Hypertension seems not to feature in the foreground of this participant's experience. Yet, when
32 some aspect of illness is perceived – not feeling 'on top hole' – her knowledge of the association
33 between hypertension and stroke means that the significance of hypertension increases.
34
35
36

37
38 Interactions with healthcare professionals also inform the meaning of illness, and several
39 participants described influential consultations where symptoms remained unexplained. One male
40 participant recalled consulting his GP over breathlessness:
41
42
43
44
45

46 *They checked my heart out and they said it's not that. Something here [points towards chest],*
47 *but it's gone no farther, so I'm not bothering them, I'm still going. They'll send for me if they*
48 *decide to do anything. (ID: 103.)*
49
50
51
52

53
54 This participant expresses trust in the expertise of his doctor and he accepts their clinical judgement.
55 Despite his unexplained symptoms, this participant's concerns are allayed and breathlessness
56 becomes part of his normal embodied state.
57
58
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1
2
3 In rare instances, interactions with healthcare professionals heightened uncertainty and suffering.
4
5 One female participant recalled consulting her GP after weeks of unexplained pain. When asked
6
7 whether her GP had resolved her concerns, she replied:
8
9

10
11 *Well, half and half really, because I wanted him to diagnose... was it sciatica? But he didn't*
12
13 *actually say that, perhaps he didn't know, because when he put me on the couch and said 'Can*
14
15 *you move, put this leg up?' He said that if I can do that, it isn't sciatica. So I just thought 'Well,*
16
17 *what is it then?' Have I pulled a muscle?' I don't know. It could be, couldn't it? But he didn't*
18
19 *diagnose anything. (ID: 110.)*
20
21

22
23 The inability of the clinician to offer a clear diagnosis appears to exacerbate our participant's suffering
24
25 as her pain assumes greater significance by virtue of its apparent senselessness. This participant lacks
26
27 an interpretive scheme by which to make sense of pain, and we might regard her experience as one
28
29 of 'embodied doubt' (Nettleton 2006) marked by uncertainty and distrust of the body.
30
31

32 33 *Discussion*

34
35
36 The aim of this study was to understand how older people living with multiple chronic conditions
37
38 make sense of ill health. **The small and homegenous sample of this study means that important**
39
40 **analytic concens (such as gender and race) are not addressed. Future research should consider how**
41
42 **such factors affect the lived experience of multiple conditions.** However, our findings problematize
43
44 two assumptions made within clinically informed literature: that multimorbidity is defined by
45
46 delimited diagnosed conditions, and that these conditions are experienced as phenomenologically
47
48 concurrent. Participants in this study questioned the relevance of diagnosed conditions, and instead
49
50 identified colloquial, undiagnosed and inchoate factors as defining features of their health.
51
52 Participants also undermined the relevance of concurrency as biomedically imagined, and spoke
53
54 instead about concurrency as biographically and temporally framed, much as depicted by Leder's
55
56 (1990) dys-appearing body. Some participants challenged the pathological lens and rejected the
57
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1
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3 label of illness altogether – ‘I’ve got the diabetes, I’ve got the blood pressure, I’ve got arthritis in my
4
5 knees, fair enough, but to me I’m not ill’. Such cases show how physical impairment and clinical
6
7 diagnoses may be incorporated into reformed visions of embodied normality. This (re)effacement of
8
9 troubled bodies stems from what Leder terms the ‘twofold telic demand’ for hermeneutic and
10
11 pragmatic action (Leder 1990; 78). Faced with illness and impairment, we strive to make sense and
12
13 to accommodate.
14
15

16
17 Normality was at the centre of most participant’s accounts, and our data confirm the differentiated
18
19 and relativistic nature of normality (Kelly and Field 1998) as participants drew on individualised and
20
21 contextualised images of what they considered to be ‘normal’. Control, or the practical efforts to
22
23 monitor and affect the course of illness, was vital to participants’ efforts to maintain, regain or
24
25 reform their desired vision of a normal life. Where control was possible, participants experienced
26
27 bodily effacement as favoured phenomenological states were attainable, whilst a lack of control
28
29 resulted in continued bodily dys-appearance and lived experiences dominated by illness.
30
31

32
33 Biography provides a context where notions of normality are formed, disrupted and reformed (Bury
34
35 1982). Our data show that the meaning of the body, impairment and specific conditions vary
36
37 according to this context. Lay interpretations of illness may seem counter intuitive from a clinical
38
39 perspective, as in the case of participant 102 who said that the pain caused by a congenital
40
41 deformity was less salient than hypertension. As discussed by Williams (2000), however, congenital
42
43 conditions and life-long impairments are often consistent with, even integral to, one’s embodied
44
45 sense of self. In such cases, the significance and consequence of these complaints are often
46
47 mitigated.
48
49

50
51 The culturally constituted link between ageing, illness, and physical decline was a prominent theme.
52
53 As in previous disease-specific studies, our data show that particular conditions within
54
55 multimorbidity such as arthritis (Sanders et al. 2002), or outcomes such as limited mobility (Grime et
56
57 al. 2010), may be interpreted as an expected feature of later life. Consequently, such diseases,
58
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3 symptoms or outcomes may be accorded less significance than aspects of ill health that are not seen
4
5 as normal, 'natural', or an inevitable part of the ageing process.
6
7

8
9 Finally, the distinction between clinical and lay schemes of knowledge is not binary, and lay people
10
11 regularly appropriate, adapt and deploy biomedical knowledge within their own sense-making
12
13 practices (McClellan and Shaw 2005). Participants drew upon biomedical concepts when making
14
15 sense of illness, and interactions with clinicians also gave meaning to illness. Yet, as our data show,
16
17 the absence of such interpretive schemes, as with undiagnosed symptoms, may just as easily
18
19 exacerbate uncertainty and suffering.
20
21

22
23 Multimorbidity understood as 'the co-existence of two or more long-term conditions in an
24
25 individual' (Mercer et al., 2009) radically truncates these complex sense-making practices. At best,
26
27 the biomedically informed concept obscures lived experience; at worst, it distorts our understanding
28
29 of the body and subject in line with biomedical presumptions. Our data show that the meaning of
30
31 multimorbidity derives not only from the physical and mental complaints deemed pathological by
32
33 the clinical gaze, but from embodied experience framed biographically and subject to wider cultural
34
35 representations. The clearest priorities of participants in this study were those associated with
36
37 selfhood, such as maintaining roles, relationships, and valued activities (Townsend et al. 2006).
38
39 'Illness prioritisation', where it did occur, appeared epiphenomenal to the prioritisation and
40
41 preservation of preferred visions of embodied selfhood through control and normality. These
42
43 findings lead us to question the concept of illness prioritisation, or the ways that people with
44
45 multiple chronic conditions choose to prioritise the self-management of certain conditions over
46
47 others. If we accept that people do not understand their health by reference to delimited diagnosed
48
49 conditions alone, and if concurrence is more complex than biomedically imagined, then prioritisation
50
51 – premised as it is upon the notion of competing, clearly identifiable and disease-specific claims
52
53 (Bratzke et al. 2015) – seems somewhat erroneous. Further, it seems unlikely that a universal or
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3 generalizable 'lived experience of multimorbidity' is attainable, nor any systematic pattern of illness
4
5 priorities discernible.
6

7
8 The clinical concept of multimorbidity is problematic because it imposes biomedical order, and
9
10 implies cognisance, modes of interpretation, and loci for action that are at odds with those of lived
11
12 bodies (Leder 1992). Multimorbidity is an epidemiological fact and a concept of clinical significance.
13
14 However it is a concept that easily leads us to misunderstand the lived experience of people living
15
16 with multiple conditions. The concept itself need not be discarded, but it must be seen as just one
17
18 model in chiasmic relation to that of the lived body: divergent concepts, which nevertheless overlap
19
20 and encroach. Privileging either model curtails our understanding both of the body and the subject,
21
22 and will lead to suboptimal practices of care. The key, we suggest, is to develop systems of health
23
24 care and education around multimorbidity that attend to both physiological and existential needs.
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40

41 Afshar, S., Roderick, P. J., Kowal, P., Dimitrov, B. D. & Hill, A. G. 2017. Global patterns of
42
43 multimorbidity: a comparison of 28 countries using the World Health Surveys. *Applied*
44
45 *Demography and Public Health in the 21st Century*. Springer.
46

47 Bayliss, E.A., Steiner, J.F., Fernald, D.H., Crane, L.A. and Main, D.S. (2003) Descriptions of barriers to
48
49 self-care by persons with comorbid chronic diseases, *The Annals of Family Medicine*, 1, 1, 15-
50
51 21.
52

53
54 Bratzke, L.C., Muehrer, R.J., Kehl, K.A., Lee, K.S., Ward, E.C. and Kwekkeboom, K.L. (2015) Self-
55
56 management priority setting and decision-making in adults with multimorbidity: A narrative
57
58 review of literature, *International journal of nursing studies*, 52, 3, 744-755.
59
60

- 1
2
3 Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of health & illness*, 4, 2, 167-182.
4
5 Bury, M. and Holme, A. (1991) Quality of life and social support in the very old, *Journal of Aging*
6
7 *Studies*, 4, 4, 345-357.
8
9
10 Charmaz, K. (2006) *Constructing grounded theory: A practical guide through qualitative analysis*.
11
12 London: Sage Publication.
13
14 Cheraghi-Sohi, S., Bower, P., Kennedy, A., Morden, A., Rogers, A., Richardson, J., Sanders, T.,
15
16 Stevenson, F. and Ong, B.N. (2013) Patient priorities in osteoarthritis and comorbid
17
18 conditions: a secondary analysis of qualitative data, *Arthritis care & research*, 65, 6, 920-927.
19
20
21 Coventry, P.A., Small, N., Panagioti, M., Adeyemi, I. and Bee, P. (2015) Living with complexity;
22
23 marshalling resources: a systematic review and qualitative meta-synthesis of lived
24
25 experience of mental and physical multimorbidity, *BMC family practice*, 16, 171, DOI:
26
27 10.1186/s12875-015-0345-3.
28
29
30 Elliott, R.A., Ross-Degnan, D., Adams, A.S., Safran, D.G. and Soumerai, S.B. (2007) Strategies for
31
32 coping in a complex world: adherence behavior among older adults with chronic illness,
33
34 *Journal of general internal medicine*, 22, 6, 805-810.
35
36
37 Faircloth, C.A., Boylstein, C., Rittman, M., Young, M.E. and Gubrium, J. (2004) Sudden illness and
38
39 biographical flow in narratives of stroke recovery, *Sociology of health & illness*, 26, 2, 242-
40
41 261.
42
43
44 Fortin, M., Bravo, G., Hudon, C., Vanasse, A. and Lapointe, L. (2005) Prevalence of multimorbidity
45
46 among adults seen in family practice, *The Annals of Family Medicine*, 3, 3, 223-228.
47
48 Francis, H., Carryer, J. & Wilkinson, J. 2018. Self-management support? Listening to people with
49
50 complex co-morbidities. *Chronic illness*, 1742395318796176.
51
52
53 Gilleard, C. and Higgs, P. (2014) *Ageing, corporeality and embodiment*. London: Anthem Press.
54
55 Glynn, L.G., Valderas, J.M., Healy, P., Burke, E., Newell, J., Gillespie, P. and Murphy, A.W. (2011) The
56
57 prevalence of multimorbidity in primary care and its effect on health care utilization and
58
59 cost, *Family practice*, 28, 5, 516-523.
60

- 1
2
3 Grime, J., Richardson, J.C. and Ong, B.N. (2010) Perceptions of joint pain and feeling well in older
4
5 people who reported being healthy: a qualitative study, *Br J Gen Pract*, 60, 577, 597-603.
6
7
8 Hughes, B. and Paterson, K. (1997) The social model of disability and the disappearing body: Towards
9
10 a sociology of impairment, *Disability & society*, 12, 3, 325-340.
11
12 Hurd Clarke, L and Bennett, E.V. (2013) Constructing the moral body: self-care among older adults
13
14 with multiple chronic conditions, *Health*, 17, 3, 211-228.
15
16 Kelly, M. and Field, D. (1998) Conceptualising chronic illness, *Sociological Perspectives on Health,*
17
18 *Illness and Health Care*. Oxford: Blackwell.
19
20
21 Leder, D. (1990) *The absent body*: London: University of Chicago Press.
22
23 Leder, D. (1992) A tale of two bodies: The Cartesian corpse and the lived body. In Leder, D. (ed) *The*
24
25 *Body in Medical Thought and Practice*. Dordrecht: Kluwer Academic Publishers. pp. 17-35.
26
27
28 Lee, E.S. (2014) *Living alterities: Phenomenology, embodiment, and race*. New York: State University
29
30 of New York Press.
31
32 Lindsay, S. (2009) Prioritizing illness: lessons in self-managing multiple chronic diseases, *Canadian*
33
34 *Journal Sociology*, 34, 4, 983-1002.
35
36
37 Mc Sharry, J., Bishop, F.L., Moss-Morris, R. and Kendrick, T. (2013) 'The chicken and egg thing':
38
39 Cognitive representations and self-management of multimorbidity in people with diabetes
40
41 and depression, *Psychology & health*, 28, 1, 103-119.
42
43
44 McClean, S. and Shaw, A. (2005) From schism to continuum? The problematic relationship between
45
46 expert and lay knowledge—an exploratory conceptual synthesis of two qualitative studies,
47
48 *Qualitative Health Research*, 15, 6, 729-749.
49
50 Mercer, S.W., Smith, S.M., Wyke, S., O'Dowd, T. and Watt, G.C. (2009) Multimorbidity in primary
51
52 care: developing the research agenda, *Family practice*, 26, 2, 79-80.
53
54
55 Merlau-Ponty, M. (2003) *The Phenomenology of Perception*. London: Routledge.
56
57
58
59
60

- 1
2
3 Morris, R.L., Sanders, C., Kennedy, A.P. and Rogers, A. (2011) Shifting priorities in multimorbidity: a
4
5 longitudinal qualitative study of patient's prioritization of multiple conditions, *Chronic Illness*,
6
7 7, 2, 147-161.
8
9
10 Nettleton, S. (2006) *The sociology of health and illness*. London: Polity Press.
11
12 Paddison, C.A., Saunders, C.L., Abel, G.A., Payne, R.A., Campbell, J.L. and Roland, M. (2015) Why do
13
14 patients with multimorbidity in England report worse experiences in primary care? Evidence
15
16 from the General Practice Patient Survey, *BMJ open*, 5, 3, DOI:10.1136/bmjopen-2014-
17
18 006172.
19
20
21 Pickard, S. and Rogers, A. (2012) Knowing as practice: self-care in the case of chronic multi-
22
23 morbidities, *Social Theory & Health*, 10, 2, 101-120.
24
25
26 Ryan, A., Wallace, E., O'Hara, P. and Smith, S.M. (2015) Multimorbidity and functional decline in
27
28 community-dwelling adults: a systematic review, *Health and quality of life outcomes*, 13,
29
30 168, DOI: 10.1186/s12955-015-0355-9.
31
32
33 Salisbury, C., Johnson, L., Purdy, S., Valderas, J.M. and Montgomery, A.A. (2011) Epidemiology and
34
35 impact of multimorbidity in primary care: a retrospective cohort study, *Br J Gen Pract*, 61,
36
37 582, e12-e21.
38
39 Sanders, C., Donovan, J. and Dieppe, P. (2002) The significance and consequences of having painful
40
41 and disabled joints in older age: co-existing accounts of normal and disrupted biographies,
42
43 *Sociology of health & illness*, 24, 2, 227-253.
44
45
46 Schoenberg, N.E., Leach, C. and Edwards, W. (2009) "It's a toss up between my hearing, my heart,
47
48 and my hip": prioritizing and accommodating multiple morbidities by vulnerable older
49
50 adults, *Journal of health care for the poor and underserved*, 20, 1, 134-151.
51
52
53 Scott, S., Prior, L., Wood, F., & Gray, J. (2005) Repositioning the patient: the implications of being 'at
54
55 risk'. *Social Science & Medicine*, 60(8), 1869-1879.
56
57
58
59
60

- 1
2
3 Slightam, C. A., Brandt, K., Jenchura, E. C., Lewis, E. T., Asch, S. M. & Zulman, D. M. 2018. "I had to
4 change so much in my life to live with my new limitations": Multimorbid patients'
5 descriptions of their most bothersome chronic conditions. *Chronic illness*, 14, 13-24.
6
7
8
9
10 Townsend, A., Wyke, S. and Hunt, K. (2006) Self-managing and managing self: practical and moral
11 dilemmas in accounts of living with chronic illness, *Chronic illness*, 2, 3, 185-194.
12
13
14 Tyack, Z., Kuys, S., Cornwell, P., Frakes, K.-A. & Mcphail, S. 2017. Health-related quality of life of
15 people with multimorbidity at a community-based, interprofessional student-assisted clinic:
16 Implications for assessment and intervention. *Chronic illness*, 1742395317724849.
17
18
19
20 Valderas, J.M., Starfield, B., Sibbald, B., Salisbury, C. and Roland, M., 2009. Defining comorbidity:
21 implications for understanding health and health services. *The Annals of Family Medicine*,
22 7(4), pp.357-363.
23
24
25
26
27 Wang, L., Si, L., Cocker, F., Palmer, A. J. & Sanderson, K. 2017. A systematic review of cost-of-illness
28 studies of multimorbidity. *Applied health economics and health policy*, 1-15.
29
30
31
32 Wei, M. Y. & Mukamal, K. J. 2017. Multimorbidity, mortality, and long-term physical functioning in 3
33 prospective cohorts of community-dwelling adults. *American journal of epidemiology*, 187,
34 103-112.
35
36
37
38
39 White, C., Lentin, P. & Farnworth, L. 2016. Multimorbidity and the process of living with ongoing
40 illness. *Chronic illness*, 12, 83-97.
41
42
43
44 Williams, S. (2000) Chronic illness as biographical disruption or biographical disruption as chronic
45 illness? Reflections on a core concept, *Sociology of Health & Illness*, 22, 1, 40-67.
46
47
48 Williams, S.J. (2002) Sleep and health: sociological reflections on the dormant society, *Health*, 6, 2,
49 173-200.
50
51
52
53 Young, I.M. (1980) Throwing like a girl and other essays in feminist philosophy and social theory,
54 *Human Studies*, 3, 1, 137-15
55
56
57
58
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Table 1. Principal Details

ID	Sex	Age group	Marital / Accommodation status	Self-identified ill-health (including OA and CVD)
101	F	65-74	Single, lives alone	Mental health (not specified), asthma, angina, reactive arthritis (eye), Raynaud's phenomenon, clawed toe.
102	M	65-74	Married, cohabits with spouse	Osteomyelitis (as a teenager), asthma, heart disease, glaucoma.
103	M	75+	Married, cohabits with spouse	Asthma, COPD, regular chest infections, stomach ulcers, 'collapsed vocal chords'.
104	F	65-74	Married, cohabits	Rheumatoid arthritis, bunions.
105	F	75+	Single, lives alone	Type II diabetes, 'underactive thyroid', glaucoma, 'breathlessness', 'fluid retention', bronchitis.
106	M	75+	Married, cohabits with spouse	Asbestosis, stomach ulcers, prostate cancer (14 years prior), COPD.

107	M	65-74	Single, lives alone	Heart attack (10 years prior), prostate cancer (2 years prior).
108	M	65-74	Married, cohabits with spouse	Heart failure, multiple TIAs, 'clubbed foot' (congenital), mild cognitive impairment.
109	M	65-74	Single, cohabits with daughter	Type II diabetes, back pain.
110	F	65-74	Single, lives alone	Depression, anxiety.
111	F	75+	Single, lives alone	Hip surgery complications (pain and mobility). 'chest weakness'.
112	F	55-64	Single, cohabits with daughter	Systematic lupus, depression, addiction (pain killers)
113	F	65-74	Married, cohabits with spouse	Congenital neuromuscular condition (limited mobility), ankylosing spondylitis, vertigo.
114	F	65-74	Married, cohabits with spouse	Fibromyalgia, coeliac disease, diverticulitis.
115	M	65-74	Married, cohabits with son	Prostate cancer (18 months prior), neck pain.

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3 Thank you to both reviewers for their comments. We have amended all typographical errors as
4 identified. The main comments of both reviewers are presented below, with our comments and
5 responses indented.
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8 Reviewer: 3
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11 "There is just one small point, which is that it would be useful to include a citation to support the
12 authors' assertions about clinical definitions and understandings of concurrence and how these are
13 contested by the qualitative data (e.g. p. 10). The authors note that the two differ, and provide
14 evidence for the patient perspective through their data, but don't really do the same for the clinical
15 definition. We are left to trust that there is in fact a difference, rather than the situation being simply
16 that these data provide rich accounts which add detail and depth to (rather than challenge/ oppose)
17 clinical understandings."
18

19
20 Thank you for this comment, which highlights a lack of precision in our argument. Valderas
21 et al. (2009) (authors who are also preeminent multimorbidity researchers) have reviewed
22 the construct of concurrence as it is employed within epidemiological science. This review
23 shows that whilst there has been some research into non-synchronous but sequentially co-
24 occurring diseases (diseases that are aetiologically linked and occur sequentially over time,
25 but do not occur at the *same* time), the majority epidemiological research assumes
26 synchronous concurrence. This review speaks only to the epidemiological literature,
27 however, and it is perhaps unwise for us to refer to this as a 'clinical' assumption (practicing
28 clinicians may not understand concurrence this way).
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31 We have included the citation of Valderas et al (2009) and have amended the manuscript to
32 refer to the epidemiological construct of concurrence, rather than the clinical understanding
33 of concurrence.
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35 Valderas, J.M., Starfield, B., Sibbald, B., Salisbury, C. and Roland, M., 2009.
36 Defining comorbidity: implications for understanding health and health services. *The*
37 *Annals of Family Medicine*, 7(4), pp.357-363.
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42 Reviewer: 1

43 "Abstract:

44 - Generally well explained, but I wondered why Constructivist Grounded Theory was not mentioned
45 if this is the analytic approach used and, in that regard, about the last sentence in which the findings
46 are described as 'a general phenomenology of multiple chronic conditions', rather than a theory?"
47
48

49 We have amended the title and abstract so that the study is not presented as a
50 phenomenological study, rather that it is informed by phenomenological theory. We have
51 included the use of CGT coding in the abstract. This point is discussed further below.
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56 "Summary:- I would suggest changing this label to Introduction or Overview (or omit an introductory
57 heading), according to the Journal conventions."
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59 This has now been done.
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3 “Methods and data collection:

4 -Information is still not included about the length of interviews, or anything about whether in-depth
5 data was generated with participants. Also, the purpose of conducting 2 interviews or the spacing of
6 them over several months is not explained.”
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8
9 Thank you for these observations, the following text has been included:

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11 Principal participants took part in up to two in-depth qualitative interviews spaced three to six
12 months apart. This design allowed for greater rapport between participant and interviewer, whilst
13 also allowing for longitudinal changes in participants’ situation to be recorded. Interviews were
14 conducted by the lead author (between 2013 and 2014) in participant’s homes, lasted between 45
15 and 90 minutes, and followed a topic guide that was iteratively refined throughout data collection.
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17 The data generated were in-depth and the each interview typically covered each participant’s history
18 of illness, the meaning of illness and the body.
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25 “Further to my previous comments, I am unsure why a phenomenological analysis was not
26 conducted, as opposed to the use of Constructivist Grounded Theory? While CGT can guide the
27 analytic process, it is also based on specific principles and aims to produce a theory grounded in the
28 data. However, elsewhere in the manuscript, the result of analysis is described as a phenomenology
29 of multiple chronic conditions, rather than a grounded theory. Again, I would suggest greater
30 elaboration on how the authors reconcile the two approaches, and/or incorporation of terminology
31 that is consistent with CGT if that is what was done.”
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33

34 “It does not seem like my previous comment regarding the need to explicate a methodological
35 approach was taken into account in the revised manuscript. The qualitative approach adopted
36 should be described, including principles of epistemology and ontology. While the theoretical
37 perspective section that proceeds outlines the lived body perspective, explanation should be given
38 as to how this perspective informed the research methodology and the way in which it was
39 conducted”
40
41

42 Thank you for these comments, which highlights a distinction between phenomenological
43 theory and method, and our lack of clarity in this regard.
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46 Our analysis followed the practical coding stages outlined by Charmaz. The focus of this
47 analysis was upon the lived experience of the body and how participants made sense of
48 illness.
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52 We did not consult phenomenological theory prior to, or during, data collection; nor in the
53 initial stages of coding. At the theoretical stage of coding, we drew upon Leder’s
54 phenomenological theory of the body in order to make our conceptualisation (or theory) of
55 lived experience clearer and more coherent. Whilst we draw extensively on
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3 phenomenological theory at this level of conceptual/theoretical interpretation, we did not
4 employ an explicitly phenomenological method.
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7 Therefore, because we did not use an explicitly phenomenological method we no longer
8 refer to this as a 'phenomenological study'. We have amended the title and abstract
9 accordingly. We have made additions to the methods section to clarify our ontological
10 understanding of the body and social action; the interpretive standpoint of CGT; and the role
11 of the researcher in constructing a conceptualisation (theory) of lived experience by drawing
12 on phenomenological theory.
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20 The ontological framing of this paper assumes that the experience of one's body is a
21 combination of both sense-data and the interpretation of this data through socio-cultural
22 schemes. Our aim is to present an account of the lived body as it is socially produced, rather
23 than to identify essential psychological structures. Therefore, whilst we draw upon
24 phenomenological theory in the conceptualisation of our data, we do not employ an explicit
25 phenomenological method. Instead we proceed from a more general interpretive
26 standpoint, which recognises the role of the researcher in the production of knowledge, and
27 the practical stages of data analysis are drawn from Constructivist Grounded Theory
28 (Charmaz 2006). The first stage of coding was 'initial coding' using line-by-line coding.
29 Following initial coding, increasingly directed and conceptually driven 'focused coding' was
30 undertaken. Focused coding involved identifying and expanding the most theoretically
31 significant and frequently occurring codes delivered through initial coding. A final stage of
32 'theoretical coding' addressed categories of codes generated through focused coding. In
33 practice, our analysis delivered a 'theory' or conceptualisation with extensive parallels to
34 existing phenomenological literature and it was during theoretical coding that Leder's (1990)
35 'dys-appearing body' was drawn upon, as a means of bringing coherent form and clarity to
36 our concepts and as a tool to 'weave the fractured story back together' (Glaser 1992: 71).
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Coding was conducted by the lead author and each coding stage was subject to review by

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3 co-authors. This involved independent coding of data by co-authors, who then interrogated
4
5 the codes developed by the lead author.
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9 “Finally, I think that the 2 sentences about limitations should be worked into the discussion
10 elsewhere, rather than being presented at the end, so the manuscript ends on a high note rather
11 than shortcomings.”
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14 We have followed your suggestion and worked the study limitations into the discussion
15 section.
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For Peer Review