

## **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.

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**Main text: 7998 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

disease entities. Morris et al. (2011) present prioritisation as a dynamic, yet deliberative process, wherein the priorities of people living with multiple conditions shift according to the ‘timing between diagnoses, prior experiences, recommended self-management activities, bereavement, contact with health services and flare-up of conditions’ (Morris et al., 2011: 153). Cheraghi-Sohi et al. (2013) argue that social context, clinical interactions, and the ability to control symptoms also shape the way lay people prioritise different conditions and symptoms. Others suggest that this complexity means self-management is unrealistic for people with multiple conditions and that alternative palliative models are more appropriate (Francis, Carryer and Wilkinson 2018).

A small number of qualitative studies question key epistemic assumptions in clinical, epidemiological and health economic readings of illness. Accordingly, self-management only partially explains the lived experience of multiple conditions, which is defined in large part by the efforts to preserve selfhood (Townsend et al. 2006) and morally valued bodies (Hurd Clarke and Bennett 2012). Pickard and Rogers (2012) further critique the epistemological basis of self-management, arguing instead for the recognition of embodied knowledge – a form of lay knowledge at odds with the ‘abstract, rational model of patient knowledge assumed in programmes like the EPP [Expert Patient Programme]’ (Pickard and Rogers, 2012: 16). These studies sit within a broader sociological tradition, which challenges biomedical readings of the body and behaviour (Cohn 2014), and point instead to role of embodied, biographical and social factors in framing the meaning of illness (Williams 2000).

Qualitative meta-syntheses of multimorbidity research reflect, and reinforce, the broader corpus. Bratzke et al. (2015) state that multimorbidity is marked by ‘competing demands’ and that people with multiple chronic conditions ‘select and order their self-management behaviours’, managing one disease at the expense of others (Bratzke et al. 2015: 753). Another synthesis depicts multimorbidity as a ‘state of complexity’ wherein conditions are ‘strategically self-managed by marshalling medical and behavioural resources to preserve self-identity’ (Coventry et al. 2015: 8). However, recent

quantitative research has shown that people living with multiple conditions identify different conditions as burdensome, suggesting that the relationship between medical diagnoses and illness experience is complex (Slightam et al. 2018).

The purpose of this study was to understand how older people living with multiple chronic conditions make sense of illness. Our aim is to provide a foundational reading of multiple chronic conditions, beginning with the premise that medical diagnoses do not *a priori* determine illness. This argument extends from immediate embodied experience to include the social and cultural schemes through which illness gains meaning. Our findings hold implications for the conceptualisation of multimorbidity and thus for healthcare organisation, delivery and education where the concept prevails.

### **Theoretical perspective**

We begin by recognising the primacy of embodiment and adopt a lived body perspective. This perspective derives from phenomenological readings of the body, juxtaposed to archetypal biomedical images of the body as mechanistic and amenable to observation, intervention and control. Prototypically outlined by Merleau-Ponty, the lived body perspective understands the body not simply as a thing-in-the-world, but as the 'medium for having a world' (Merleau-Ponty 2003: 169). The body is a medium in our sense-making practices because, unlike inanimate objects, it is intentional and directed towards an experiencing world. Through this intentionality both the body, and the world, become meaningful. As Leder states: 'we cannot understand the meaning and form of objects without reference to the bodily powers through which we engage them – our senses, motility, language, desires. The lived body is not just one thing *in* the world, but a way in which the world comes to be' (Leder 1990: 123).

A second tenet of our analysis is that the body, in the absence of illness, is characterised by effacement. Leder (1990) outlines a phenomenology of the 'normal' body as characterised by three

forms of bodily disappearance: *focal disappearance* whereby organs disappear from perception when they form the focal origin of our perceptual field, *background disappearance* whereby bodily regions disappear into a general 'corporal gestalt' (Leder 1990: 26), and *depth disappearance* whereby visceral organs and vital functions recede from awareness because they do not directly perceive or act upon the world (Leder 1990: 53). When we become ill or experience pain, our perceptual schemes transform, and that which was once invisible becomes visible; bodies become 'opaque' as they enter into subjectivity as an alien presence (Leder 1990: 82). The body and its visceral processes become apparent through their dysfunction, a shift Leder coins *dys-appearance*.

Once apparent, pain and illness make a twofold 'telic demand' upon the subject for hermeneutic and pragmatic action (Leder 1990; 78). Hermeneutic action calls for the subject to make sense of impairment, whilst the pragmatic moment compels control over the body. These demands open the lived body onto myriad socio-cultural schemes of meaning, as well as social and material opportunities and constraints for action. It is acted upon through intersubjective and material interactions, and is interpreted through cultural schemes inscribed by relations of power – the body becomes gendered (Young 1980), racialized (Lee 2014), aged (Gilleard and Higgs 2014) and oppressed (Hughes and Paterson 1997). Embodiment thus conceived involves a subject-object dialectic whereby the body is simultaneously perceiver and perceived, and neither the body, nor the world it inhabits, may be understood without this relation.

This paper adopts a lived body perspective to delineate lived experiences of multiple conditions, and to highlight interactional and interpretive schemes that give meaning to the *dys-appearing* body.

### **Methods and data collection**

The data presented in this paper are taken from the lead author's UK based doctoral research.

Ethical approval was attained from the regional National Health Service Research Ethics Committee.

Principal study participants (those with multiple conditions) were purposively sampled and recruited from an existing cohort study, the XX study (XX). The XX study sample contained older adults with clinical diagnoses of osteoarthritis (OA) and cardiovascular disease (CVD), including hypertension, heart disease, and heart failure. The current study recruited from a subgroup of XX participants who consented to further contact. These participants had a historic diagnosis of OA and CVD, however all reported additional chronic and episodic conditions during interviews (outlined in Table 1).

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

Principal participants took part in up to two in-depth qualitative interviews spaced three to six months apart. This design allowed for greater rapport between participant and interviewer, whilst also allowing for longitudinal changes in participants' circumstances to be recorded. Interviews were conducted by the lead author (between 2013 and 2014) in participant's homes and followed a topic guide that was iteratively refined throughout data collection. The data generated were in-depth and the each interview typically covered each participant's history of illness, the meaning of illness and the body. Prior to interviews, participants were given study information sheets in accessible formats. All participants provided informed consent prior to interviews and this was reaffirmed after each interview. Interviews were transcribed verbatim, with all personally identifying information removed. Data storage and administration were conducted using QSR Nvivo 10 on password protected servers.

The sample consisted of eight female and seven male participants; three female spouses and one male spouse were also recruited. Participants were aged 59-84. Five participants lived alone, ten cohabited. Seven participants were single, eight were married. The sample was ethnically and culturally homogenous; fourteen participants were white British, one participant was white non-

British. The employment status of the sample was also homogenous; thirteen participants were retired, one worked full-time, one worked part-time.

The ontological framing of this paper assumes that the experience of one's body is a combination of both sense-data and the interpretation of this data through socio-cultural schemes. Our aim is to present an account of the lived body as it is socially produced, rather than to identify essential psychological structures. Therefore, whilst we draw upon phenomenological theory in the conceptualisation of our data, we do not employ an explicit phenomenological method. Instead we proceed from a more general interpretive standpoint, which recognises the role of the researcher in the production of knowledge, and the practical stages data analysis are drawn from Charmaz's (2006) Constructivist Grounded Theory. The first stage of coding was 'initial coding' using line-by-line coding. Following initial coding, increasingly directed and conceptually driven 'focused coding' was undertaken. Focused coding involved identifying and expanding the most theoretically significant and frequently occurring codes delivered through initial coding. A final stage of 'theoretical coding' addressed categories of codes generated through focused coding. In practice, our analysis delivered a 'theory' or conceptualisation with extensive parallels to existing phenomenological literature (Leder 1990) and it was at the stage of theoretical coding that Leder's (1990) 'dys-appearing body' was drawn upon, as a means of bringing coherent form and clarity to our concepts and as a tool to 'weave the fractured story back together' (Glaser 1992: 71).. Coding was conducted by the lead author and each coding stage was subject to review by co-authors. This involved independent coding of data by co-authors, who then interrogated the codes developed by the lead author.

The study did not raise any particular ethical concerns, apart from asking participants to discuss potentially upsetting topics. These discussions were conducted so that participants retained control; the interviewer took care to remind participants they could pause or stop the interview at any time.

## 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 in a synchronous manner. 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:



*If I was ill I'd be in pain... stomach, chest, the bits that matter in the middle. That's being ill to me. You've got no control over it... Appendicitis or if you've got bloody transplants, that's being ill... [Whereas] If you break your arm, you're not ill. It's a bloody inconvenience. It's like my knees, they're an inconvenience, but it's something you've got to put up with. (ID: 109.)*

Impairment transforms the meaning of the material environment and thus the body. However in this case the transformation is relatively minor, an inconvenience, rather than an experience dominated by disability. Our participant has a clear understanding of what it means to be an 'ill person'. Illness means losing control, diseased visceral organs, or complex clinical interventions. In the absence of these signs or symptoms, this participant, despite multiple diagnoses, understands his health as the practical limitations impairment confers.

Another participant, a woman living with systemic lupus, OA, depression, and an addiction to opioid medication, expressed similar reasoning. This participant was a nurse by profession and recognised the importance of multimorbidity to clinical practice. Despite this, when describing her own experience of illness, she questioned the relevance of multimorbidity as clinically imagined:

*I don't look at myself as this ill person with all these things going on. Even on the worst day, it was always because it was one particular thing that was the problem at the time. So anything else associated or not associated with that didn't really come into... if it was arthritis that was the problem, then that was the problem. (ID: 112.)*

This participant questions the label of illness and problematises the synchronous basis of concurrency. Concurrency, as is generally imagined within epidemiological literature (Valderas et al. 2009), assumes the simultaneous presence of multiple conditions. Yet as this participant explains, the lived experience of concurrence is characterised by fluctuating symptoms, meaning that a single symptom or condition may dominate experience at any one time. Redolent of Leder's (1990) dys-appearing body, symptoms and conditions slip in and out of apprehension according to their

perception. Thus, we can say that whilst concurrence is a defining feature of multimorbidity as an object of biomedical knowledge, concurrence does not define this participant's experience of multiple conditions.

Several participants made reference to 'borderline' conditions when describing their health, and where this occurred, the ambiguity between embodied experiences and clinical diagnoses problematized concurrence further. The following quotations, both from female participants, are exemplary:

*I had a diabetic foot in October and nearly lost my toe; it went black. I'm borderline diabetes; I'm not classed as a diabetic. (ID: 101.)*

*My blood pressure has fallen again but only, probably just in the zone he [consultant] wanted which was... was it 70 over? No 100 over – I can't remember. Something over 70... he said, "Well, it's borderline". (ID: 104.)*

The 'borderline' status of diabetes and hypertension means these conditions are experienced as simultaneously present and absent. Illness is present insofar as both participants have an awareness of risk, which may require preventative or remedial action. At the same time the 'borderline' status denotes illness as absent – as the first participant explains, 'I'm not classed as a diabetic'. These excerpts highlight the importance of inchoate aspects of ill health (Scott et al. 2005) as the latent possibility of illness shapes how both women understand their bodies and the meaning of their health.

Other participants spoke about illness in ways that highlight a more general dissonance between diagnosed conditions and the lived experience of multimorbidity.

*I have a chest problem which just flares up now and again, but I've had that for a lot of years. It's not chronic, but it's just that sometimes I wheeze quite a lot and other times it's okay. I had*

*bronchitis a long time ago. I had to go to the chest clinic... The only diagnosis they could come up with was bronchitis. It wasn't a permanent thing. Even in this warm weather, people would say to me, 'Have you got a bad cold?' I haven't, it's just the rustiness in my throat. (ID: 111.)*

This participant's 'chest problem' was among her most salient concerns, yet in the absence of a clear clinical explanation its meaning remains ambiguous. One explanation may be that her 'weakness' is a sign of chronic bronchitis, but she understands this issue differently. This complaint gains significance only when our participant perceives it as a physical impairment, or when others recognise it during interactions. Once perceived, lay terminology of 'weakness' and 'rustiness' help bring sense to her symptoms.

### **Lay logics of meaning**

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

### *Normality and control*

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

*It's there, these things... one, two or three, whatever you've got, arthritis, asthma, you've just got to live with it. It's there and until I start coughing, you just carry on as normal. Just carrying on until you try to do something, getting stuff out of a cupboard or something, then you realise that you've got that condition. (ID: 102.)*

This excerpt illustrates how individual conceptions of normality act as a foundation upon which illness gains meaning. Our participant describes being able to 'carry on as normal' despite living with multiple conditions, and it is only when some aspect of daily life becomes impeded that illness is comprehended. When normality is impinged it is those disrupting features of illness are propelled to the foreground of experience.

Another male participant shed further light on the link between disrupted normality and the meaning of multiple conditions:

*I'm living with these aches and pains, as it were, you know? But quite often, while this weather's been on, I've started coughing when I'm in bed and I've had to get up. I may have gone to bed about 10 or 12 o'clock, and I've had to get up because I'm coughing that much... The night's worse with this with asthma, it's so long if you are coughing during the night.... It's a long time till breakfast. (ID: 103.)*

Our participant says that the 'aches and pains' associated with OA are not so onerous as to prevent normality, whilst sleepless nights caused by episodes of coughing are more disruptive. This is understandable given that sleep is a socially organised practice, which gives meaning and order to our social worlds (Williams 2002). The disruption of sleep means the disruption of normal life, of typical patterns of interactions and activities. The statement 'It's a long time till breakfast' conveys the isolation and suffering that mark these experiences, and explains why asthma and cough dominate this participant's experience of illness.

Control engenders normality and participants spoke about control as the means of attaining embodied normality, as the motivation for self-management activities, and shaping the meaning of illness in prospective terms. For many, medication was the primary means of recovering control over illness and the body.

*As long as the medication is controlling the blood pressure, I should be fine. As long as I take the eye drops – I can't focus with one eye, I have a problem with one eye, and that's been the situation since I was a child really. I've basically only got one good eye. If I was to lose that, then I would have serious issues, but I'm told that as long as I continue taking the drops; as long as I attend the eye clinic regularly, for them to check the eye pressures, then hopefully, everything's under control. (ID: 102.)*

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

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

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

Dietary changes and medication have enabled control and allayed the threat posed by this condition to health, the body and everyday life. With control, the significance of diabetes diminishes and our participant appears untroubled by this diagnoses.

The importance of control was underscored where participants spoke of being unable to control illness and the body. One participant described his experiences following radical prostatectomy and his struggle to come to terms with incontinence:

*I'm 18 months on and I've still got a nappy on, which sickens me at times it really does. You're going out and you think, "Bloody hell, I'd better go and have a wash and change that" because you think you can smell yourself. It's not very nice. (ID: 107.)*

This case illustrates clearly the link between control and normality, and shows how a lack of bodily control can frustrate efforts to regain normality. Incontinence is experienced as an acute lack of control, both physically and emotionally, as shame and embarrassment threaten to undermine this participant's sense of self. Incontinence and its associated stigma anchor this participant's life in illness; 18 months after surgery, his distress at the lack of normality is palpable.

#### *Biography and normality*

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

When asked to describe his overall health, one male participant listed OA, heart disease, and hypertension. Prompted to give a fuller picture of his health, this participant proceeded to identify another health concern:

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

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

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

Another male participant expressed similar reasoning when talking about his congenital foot deformity:

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

Int: *So you don't consider that a health problem?*

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

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

### *Age and normality*

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

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

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

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

A female participant expressed similar views when talking about recent reductions in her mobility:

*I think that the last 12 months perhaps it has gone, deteriorated a little more. But all I can say is that it's something I have to accept. Of course, my own body as well, my age doesn't help because you're obviously not agile anymore. But as I say, I'm grateful that I am where I am.*

(ID: 111.)



At the same time, participants also associated specific conditions with later life:

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

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

#### *Biomedicine and health professionals*

Biomedicine and interactions with health professionals provide a further interpretive scheme. Several participants spoke about risk factors, clinical prognoses, and pathophysiological associations when making sense of their health. One male participant drew upon such concepts when explaining the meaning of cancer and hypertension:

*Cancer is the one that preys on you, really... because they can sneak back anytime. So as long as I can keep that in, I can manage. Because, the other week when I went for my annual check-up with my GP, my blood pressure was 135/74, which is pretty good. He said everything's all right there, so that's under control. (ID: 107.)*

This participant deploys basic biomedical knowledge to make sense of illness. He presents cancer and hypertension within a hierarchy of risk, in which cancer supersedes hypertension due to the

risk of reoccurrence and mortality. Hypertension is also framed biomedically through the reporting of blood pressure readings, which appear to afford this participant a sense of control.

Risk factors were widely referenced by participants, and hypertension in particular became meaningful through its association with cardiovascular events. One female participant said that hypertension was not 'on her radar' because it was controlled by medication. However, when asked how she would feel if her blood pressure were to rise, she replied 'I'd be thinking strokes, heart attack' (ID: 112). Another female participant said:

*I wouldn't say that I think about it [hypertension], but if you don't feel well, or sometimes you'll get up and you'll not feel on top hole, you do think about it, because something that you worry about more than anything at this age is strokes. Of course, with blood pressure, you do think about it a bit like that. (ID: 111.)*

Hypertension seems not to feature in the foreground of this participant's experience. Yet, when some aspect of illness is perceived – not feeling 'on top hole' – her knowledge of the association between hypertension and stroke means that the significance of hypertension increases.

Interactions with healthcare professionals also inform the meaning of illness, and several participants described influential consultations where symptoms remained unexplained. One male participant recalled consulting his GP over breathlessness:

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

This participant expresses trust in the expertise of his doctor and he accepts their clinical judgement. Despite his unexplained symptoms, this participant's concerns are allayed and breathlessness becomes part of his normal embodied state.

In rare instances, interactions with healthcare professionals heightened uncertainty and suffering. One female participant recalled consulting her GP after weeks of unexplained pain. When asked whether her GP had resolved her concerns, she replied:

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

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

### *Discussion*

The aim of this study was to understand how older people living with multiple chronic conditions make sense of ill health. The small and homogenous sample of this study means that important analytic concerns (such as gender and race) have not been addressed. Future research should consider how such factors affect the lived experience of multiple conditions. However, our findings problematize two assumptions made within clinically informed literature: that multimorbidity is defined by delimited diagnosed conditions, and that these conditions are experienced as phenomenologically concurrent. Participants in this study questioned the relevance of diagnosed conditions, and instead identified colloquial, undiagnosed and inchoate factors as defining features of their health. Participants also undermined the relevance of concurrency as biomedically imagined, and spoke instead about concurrency as biographically and temporally framed, much as depicted by Leder's (1990) dys-appearing body. Some participants challenged the pathological lens and rejected

the label of illness altogether – *‘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’*. Such cases show how physical impairment and clinical diagnoses may be incorporated into reformed visions of embodied normality. This (re)effacement of troubled bodies stems from what Leder terms the ‘twofold telic demand’ for hermeneutic and pragmatic action (Leder 1990; 78). Faced with illness and impairment, we strive to make sense and to accommodate.

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

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

The culturally constituted link between ageing, illness, and physical decline was a prominent theme. As in previous disease-specific studies, our data show that particular conditions within multimorbidity such as arthritis (Sanders et al. 2002), or outcomes such as limited mobility (Grime et al. 2010), may be interpreted as an expected feature of later life. Consequently, such diseases,

symptoms or outcomes may be accorded less significance than aspects of ill health that are not seen as normal, 'natural', or an inevitable part of the ageing process.

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

Multimorbidity understood as 'the co-existence of two or more long-term conditions in an individual' (Mercer et al., 2009) radically truncates these complex sense-making practices. At best, the biomedically informed concept obscures lived experience; at worst, it distorts our understanding of the body and subject in line with biomedical presumptions. Our data show that the meaning of multimorbidity derives not only from the physical and mental complaints deemed pathological by the clinical gaze, but from embodied experience framed biographically and subject to wider cultural representations. The clearest priorities of participants in this study were those associated with selfhood, such as maintaining roles, relationships, and valued activities (Townsend et al. 2006). 'Illness prioritisation', where it did occur, appeared epiphenomenal to the prioritisation and preservation of preferred visions of embodied selfhood through control and normality. These findings lead us to question the concept of illness prioritisation, or the ways that people with multiple chronic conditions choose to prioritise the self-management of certain conditions over others. If we accept that people do not understand their health by reference to delimited diagnosed conditions alone, and if concurrence is more complex than biomedically imagined, then prioritisation – premised as it is upon the notion of competing, clearly identifiable and disease-specific claims (Bratzke et al. 2015) – seems somewhat erroneous. Further, it seems unlikely that a universal or

generalizable 'lived experience of multimorbidity' is attainable, nor any systematic pattern of illness priorities discernible.

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

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Table 1. Principal Participant Details

<b>ID</b>	<b>Sex</b>	<b>Age group</b>	<b>Marital / Accommodation status</b>	<b>Self-identified ill-health (in addition to OA and CVD)</b>
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.