



Health, illness and frailty in old age: a phenomenological exploration

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ABSTRACT

The aim of this paper is to subject the clinical classification of frailty to scrutiny through exploring, via a phenomenological lens, the lived experiences of older people who meet the objective, or clinical, criteria of frailty. Drawing on a range of published research that explores the heterogeneous experiences of embodied ageing, the paper highlights the continuity of phenomenological structures of experience across successful ageing, normal ageing and frailty, suggesting the permeability and contestability of the boundaries between them and highlighting the complexity of health and illness in old age. Such data suggests a need to question the perception of frailty as something both apart from ‘normal’ ageing, and constitutive of frailer or failed ageing, and challenges the construction of the third age/fourth age polarity that underpins much of the meaning accorded to old age today.

Background: the contested concept of ‘frailty’

Classifying an older person as frail takes place according to contrasting, and contested, criteria within the health and social care professions and is disputed by patients themselves (Manthorpe & Iliffe, 2015). Within the medical profession no one definition, or indeed aetiology, prevails although there are two main approaches (Pickard, 2014). The Fried et al. model (2001) defines frailty as a specific ontological state, identifiable through the presence of three or more of the following characteristics: unintentional weight loss; exhaustion; weakness; slow walking; and low activity level. Together these are indicative of a ‘tipping point’ physiologically ushering in a state of profound ontological vulnerability, in which even a minor event can precipitate collapse. The deficit accumulation model (Rockwood & Mitnitski, 2011) is more pragmatic and calculates a ‘risk’ index according to where one is positioned on this grid. Both models are concerned with employing frailty to anticipate the likelihood of ‘adverse outcomes’ in terms of falls, hospitalisation and death. Neither, however, tell us what frailty actually is; although distinguished from disability and chronic illness (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004), frailty often accompanies both of the latter, especially in old age, and where they end and frailty begins is uncertain. This perhaps explains why geriatricians still rely on subjective judgements as in the claim to ‘know it when I see it’ (Korenvain et al., 2018). In practice it may be more helpfully seen as signalling the need for a type of service organisation

than as defining a patient category: for example indicating the need for a more holistic approach to treating older patients with complex needs, both within healthcare and across the health and social care boundary (Manthorpe & Iliffe, 2015). Certainly the vignettes in the British Geriatrics Society’s (BGS) best practice guidance ‘Fit for Frailty’ (BGS, 2017), which depict a number of frail older people receiving carefully planned and integrated interventions to reverse frailty suggests the latter (see ‘Eric’s Story; Phyllis’ story; ‘Ken’s Story’ among others, p. 18)¹.

However, although the definition and measurement of frailty is disputed between clinicians the most important difference distinguishes the approach of the former from that of older people themselves. The prevailing perceptions of older people (both frail and non-frail) taken from a range of empirical studies (e.g. Britain Thinks, 2015; Grenier, 2007; Puts, Shekary, Widdershoven, Heldens, & Deeg, 2009; Schoenborn, Rasmussen, Xue, et al., 2018; Warmoth, Lang, Phoenix, et al., 2016), demonstrate that, whilst recognizable in other people, frailty is not perceived to apply to them, being the mark of the (feared and pitied) Other; that the label itself has pernicious effects requiring resistance if applied to self; that it refers to a state of irremediable and terminal decline; that while there may be some overlap with clinicians’ views on what conditions are associated with frailty, not all conditions associated with the definition – for example lack of energy or speed of walking - unequivocally relate to frailty in lay experience; and similarly that there is a difference between a label of frailty and a lived

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¹ For example, although his GP thought Eric had frailty, it was found that his complex symptoms were the result of a combination of carpal tunnel syndrome and hypotension and once Eric was receiving appropriate medications and physio he no longer fell and was restored to full functionality. Similar accounts of other patients being ‘cured’ with appropriate medication or care packages demonstrates nothing specific about frailty in any of the examples in this guide.

experience of frailty. Importantly, missing from clinical models is the sense of any qualitative shift, or threshold, in terms of capacities relating to valued attributes such as personal self-care, or subjective well-being (Britain Thinks, 2015). As such, clinical interventions are aimed at building muscular strength and increasing fitness through diet and exercise, with currently limited evidence of any real or sustained effectiveness (Puts et al., 2017). Furthermore, older people see certain symptoms, particularly psycho-social symptoms, to be the cause as much, if not more, than the effect of frailty as apparent in the following statement: 'I think frailty is a state of mind... thinking of yourself as frail then you gonna have some subsequent frail behaviour' (Schoenborn et al., 2018: 4). There is a trend in the research literature to label this 'psychological' frailty but such a label makes a distinction between mind and body that is not sustainable, either empirically or conceptually. Finally, a theme that is highlighted by a small number of social scientists, yet overlooked entirely in the clinical literature, is the fact that many older people classed as frail also enjoy positive aspects of embodiment and maintain objective strengths (Nicholson, Gordon, & Tinker, 2017; Nicholson, Meyer, Flatley, et al., 2012; Nicholson, Meyer, Flatley, & Holman, 2013; Van der Vorst, Zuilstra, et al., 2017).

The fact that medical definitions of frailty have developed without reference to lay views and experience would not matter so much if frailty were a disease, or 'objective biological entity' (Hughes, 2016) of the sort identifiable via a blood test or scan. On the contrary, however, normal ageing and frailty clearly exist on a continuum and furthermore attributes of both are deeply value-based. Indeed, the label of frailty reifies certain socially valued attributes as 'healthy' (productiveness, autonomy, speed, social engagement and so on) suggesting a particularly late modern 'moral economy of the frail body' (Pickard, 2014:557) shared across medical and social categories. This is also linked with the professional project of geriatric medicine where identification and management of frailty is increasingly considered one of its key roles (Pickard, 2014). Here, 'successful' ageing, as heralding the third age, and frailty, as marker of the fourth, operate as a binary. Both are equally contestable as is the normative framework built upon them, with alternatives to the focus on success/failure including, inter alia, ageing 'well' or ageing authentically (see Hughes, 2016; Laceulle, 2017) and highlighting the role of social inequality and precarity in frailty (Grenier, Lloyd, & Phillipson, 2017) as opposed to the view of frailty as an individual problem (and successful ageing an individual achievement).

Such evidence also suggests that in order to explore frailty both as it is conceived clinically and as it is experienced and lived it is necessary first to understand the unique nature of health and illness in old age.

Health and illness in old age

In geriatric medicine as it evolved in the nineteenth and early twentieth centuries, clinical approaches posited different ontological norms of the older body, where a fine line separated illness from health. This can be traced back to nineteenth century French physician Jean-Martin Charcot who noted that 'the textural changes which old age induces in the organism sometimes attain such a point that the physiological and the pathological state seem to mingle... and to be no longer sharply distinguishable' (1881:20). Following the work of Charcot's colleague, Claude Bernard, as biomedicine developed the trend was towards assessing physiological functioning in relation to the polarity between normality and pathology, a trend which has become entrenched as medicine has consciously sought to be more 'scientific'. Geriatric medicine was founded, however, on more traditional understandings. Georges Canguilhem, in his great thesis on the philosophy of knowledge, specifically the nature of biological and medical knowledge, published originally in 1963, expounded, and endorsed, this older view of the relationship between health and disease. In this tradition, health involves not resistance to change, as in Bernard's concept of homeostasis (which is derived from the Greek meaning 'staying the

same') but rather the ability to cope with change. Indeed, Canguilhem (1978) explained health as 'the possibility of transcending the norm, which defines the momentary normal, the possibility of tolerating inflections of the habitual norm and instituting new norms in new situations'. Conversely, 'disease is characterised by the fact that it is a reduction in the margin of tolerance for the environment's inconstances' (pp 115–6). Although old age also involves a reduction in the margin of tolerance to external challenges it is *not* thereby synonymous with disease: Canguilhem is clear that old age must not be judged by the norms of other life stages and sees the normality of old age as a 'recognition of the individual and chronological relativity of norms' (1978: 284) (see Tiles, 1993, for a discussion of the importance of Canguilhem's arguments in this respect).

However, countering this trend is the response by modern cultures to the increasingly profound fear of ageing through the 'psychologically primitive strategy' (Cole, 1992:230) of splitting the good from the bad. This tendency underlies the most sophisticated contemporary medical approaches, from Rowe and Kahn's (1987, 1997) separation of the elite 'successful' agers from the 'usual' or 'normal' agers and the rest, to the biogerontological equation of biological ageing with pathology per se². Looking at frailty models in this light, as it developed into a medical nosology from the turn of the twenty-first century, frailty has come to represent the incorporation of geriatric medicine more fully into scientific medicine as we can see if we take a brief historical review. In its earliest form, Rockwood's model (1994) was based on a notion of dynamic balance between positive and negative factors in everyday life which included social as well as medical factors, assets as well as deficits. However, subsequent versions of the model, from 1999 onwards, discarded reference to the co-existence of positive constituents and became the deficit accumulation model/frailty index, sharing the assumption that change in relation to ageing lies in only one direction (namely deficit) and should thus be resisted. All such models, moreover, have been based on laboratory and mathematical reasoning as opposed to clinical practice and expertise. Both major frailty models are also consistent with a contemporary trend in medicine which maintains the centrality of standard norms across the adult lifecourse (Pickard, 2012). Within such a framework, the boundaries between 'normal' ageing, illness in old age and frailty are increasingly quantitatively, and narrowly, defined. As such, the medical approach and the social classification proceeds hand in hand, rendering 'youth' a social virtue and aspiration, whilst also synonymous with health; in deep old age the boundary with the fourth age is simultaneously a failure of will and a clinical 'systems failure'. Thus, Rockwood et al.'s balance beam model (1994) reminds us of how much has been lost from later clinical models, in offering not just a more holistic and sympathetic view of older bodies, but of the place of old age in society.

Aims and methodology

The aim of this paper is to subject the classification of frailty to greater scrutiny through exploring the lived experiences of older people who meet the clinical criteria for this diagnosis. To do this, I carried out a secondary analysis of a small number of published qualitative studies consisting of rich empirical data which I interpreted through a phenomenological framework. I drew upon a range of papers presenting data on health and illness in old age generally and frailty specifically

² Although Rowe and Kahn (1987) accept the 'normal' series of changes with ageing in the body they suggested that 'successful' agers showed far less of these changes. They thus cautioned that some of the so-called normal changes attributed to age were no such thing but rather the result of individual lifestyle factors and thus modifiable and preventable rather than 'natural'. Whilst helpful in many ways, such as in placing an emphasis on prevention, this research theme has led, especially when fed by research in the cellular biology of ageing, to a view that normal ageing is pathological per se, as well as to the substitution of health with normativity.

(15 and 12 papers respectively in each category) in order to explore as a whole the lived experience of embodiment in old age³. This enabled me to identify and explore the continuity of embodied structures across all categories and to highlight the permeability and elusiveness of the boundaries between them. In addition, the paper explores the variety of experiences that receive little or no attention or recognition in current clinical approaches, especially the positive and dynamic aspects of living with frailty. The broader aim is to contribute to the literature that challenges the social imaginary of frailty as failed (or ‘frailied’) ageing (Grenier et al., 2017) and thus to reduce the power currently inherent in the cultural construction of the ‘fourth age’ (Gilleard & Higgs, 2011). It draws inspiration thus from Canguilhem's observations and indeed much of Canguilhem's thesis is supported by phenomenological concepts, such as its emphasis on lived space over objective space and on a view of health as involving subjectivity.

Whilst, with very few exceptions, most of the papers I draw upon are not themselves phenomenological by design a key task of my analysis was to interpret them through the lens of this philosophical methodology. Thus, I read the papers alongside key concepts derived from phenomenology, iteratively working from the data to the concepts and back again in order to link what was mostly atheoretical or thematic descriptive material to this body of theory. Through this process I was able to build a richly textured understanding of the structures of lived experience involved in a diverse variety of forms of embodiment in old age. A particular, perhaps unique, benefit of phenomenology is its ability to bring to light the taken-for-granted quality of normality, together with its breakdown, which it does by placing *embodied* experience at the centre of its analysis. As noted, it also provides much more than a purely descriptive account, where theory structures descriptive data at every stage (Davidson, 2000). I am not, however, suggesting that phenomenology is the *only* way of understanding health and illness in old age; indeed it can be used alongside both clinical approaches and other approaches within the social sciences, such as narrative analysis (eg Pound, Gompertz, & Ebrahim, 1998; Sanders, Donovan & Dieppe, 2001; Nygren, Norberg, & Lundman, 2007; Richardson, Grime, & Ong, 2014; Browne-Yung, Walker, & Luszcz, 2017). At the same time, laying bare the structures of experience offers the possibility of avoiding the well-rehearsed problems associated with narrative accounts whereby older people may normalize or downplay illness from a disposition of stoicism, a desire to minimize perceived burden on others, or from low expectations of ageing itself (see Pound et al., 1998). It also offers to more practice-oriented thematic accounts a way of linking themes to an overarching framework, demonstrating how the parts, or themes, fit together into a whole.

In the next section I provide a brief overview of phenomenological concepts.

Phenomenology: key principles

Deriving from the philosophy of Husserl (1931), Heidegger (1962) and Merleau-Ponty (1962) [2002], among others, phenomenology

³ I identified qualitative studies of living with frailty using the database CINAHL and the search terms ‘frailty’ plus: ‘qualitative’; ‘empirical’; ‘lived experience’. In addition, I searched electronic archives of key journals from the past ten years namely Social Science and Medicine, the Gerontologist, Ageing and Society, Journal of Aging Studies, Sociology of Health and Illness and Journal of Advanced Nursing, supplementing these with snowballing techniques including following up of interesting references together with citations in Google Scholar. I performed a similar search to find qualitative research in health and illness in old age more generally, using the search terms ‘old age’ plus: ‘health’, ‘illness’, ‘resilience’. However, in all this I did not aim to be exhaustive; my aim was to identify a range of richly detailed empirical accounts involving a first-person perspective sufficient to subject to a secondary analysis using phenomenological concepts, and many of which I directly draw on for my data in this paper.

takes as its starting point a first-person perspective from which cultural and scientific rationalisations and interpretations are bracketed out by means of the phenomenological *Epoche* and focus given to the things in themselves⁴. In the case of both frailty and embodied ageing more generally, this requires suspending medical approaches and assumptions about what normal or healthy ageing is and equally suspending the youthful gaze which (operative equally in medicine as in culture more broadly) assumes youthful embodiment as the norm. For Merleau-Ponty, Cartesian assumptions about the duality of mind and body have, further, to be left aside as the self is essentially embodied. Merleau-Ponty makes central the notion of motor intentionality, which comprises simultaneously cognitive and corporeal dimensions. Within this framework, objects are never just things, but have meanings in terms of the projects and goals they facilitate, replacing ‘I think’ with ‘I can’ as a fundamental principle of consciousness (Merleau-Ponty, 2002: 159). A bicycle, for example, or a walker or wheelchair, is not just a metal structure enabling travel but a means to get to work, socialise, express independence or a personal philosophy. Relationships with other people, as well as formal and informal support, can also underpin and make possible this intentionality.

Phenomenologically, ‘I can’ is closely related to health: Gadamer defines health as ‘not a condition... that one introspectively feels in oneself. Rather, it is a condition of being involved, of being-in-the-world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks’ (1996: 113; 144–5; quoted in Aho, 2018). Furthermore, perception operates according to a gestalt relation, wherein the body schema is a mix of presence and absence depending on the task and activity in which it is engaged; similarly, as Canguilhem points out, ‘the state of health is a state of unawareness where the subject and his body are one’ (1978: 91), a state of equilibrium which Leder (1990) terms disappearance and which produces a habitual body. Being dynamic, this habitual body has to be asserted continually, albeit tacitly, and it can also be disrupted or damaged; illness in old age and frailty specifically can thus be seen as a rupture to this state. Furthermore, the perceived possibilities of our lives comprise a structure which Husserl calls a ‘horizon’ and which has a temporal and spatial dimension characterised by a projection outwards in space, towards projects and towards others, and forward in time, towards the future (Toombs, 1991: 258). Lived temporality and spatiality cannot be captured by objective measurements (as in the speed or distance one can walk, captured in the up-and-go tests for frailty (see Savva et al., 2013)) but they are rather ‘both perceived and produced through the activities we engage in’ (Davidson, 2000: 644).

Human beings exist within a certain mood(s), which is a state prior to cognition, an affective atmosphere in which we live and relate to the world (Aho, 2018). This informs the intentional mode of being and involves a ‘fusion of physical-psychic states’ (Freund, 1990:458). So for example ageism and the cultural script of deficit as well as more personally experienced obstacles and challenges will have an impact on the mood of later life which in turn impacts on one's well-being and physical functioning; it is thus possible to view frailty in part as a somatic expression of a despairing mood.

The final key point to draw attention to for the purposes of this paper is that, although the first-person perspective is intrinsic to phenomenology, when using phenomenology as a tool to understand the everyday experience of others, it is important to guard against the idea that ‘understanding’ involves a process of simply putting oneself in the

⁴ *Epoche*, from the Greek, means that we refrain from judgement, involving both the commonsense and scientific knowledge that characterises the ‘natural attitude’; instead we ‘learn to see what stands before our eyes, what we can distinguish and describe’ (Moustakas, 2011: 33; original emphasis). This is not the same as the Cartesian reduction, however, as it does not doubt the reality of everything, simply that of the beliefs and knowledge that comprise the natural attitude.

shoes of another person. Through the first-person perspective, 'everything I know about your conscious life is really based on my knowledge of my own lived experiences' (Moustakas, 2011: 38; original emphasis). This is particularly problematic in the case of older people as it involves tacitly judging their embodied dispositions through a youthful perspective. Matthew Ratcliffe (2012) suggests instead the use of 'radical empathy'. Like phenomenological methods more generally, radical empathy involves switching off all conceptual or theoretical approaches or everyday assumptions that make up one's own world and instead being aware of subtle differences in terms of the other's world. However it is also specifically attuned to the presence of subtle differences in terms of the other's lifeworld, appreciating that a shared world, where it occurs, is an achievement. This approach requires familiarity with the other person's narratives and history, including their horizontal structure such as their sense of temporality associated with age and stage and their orientation towards aims and goals, as well as their everyday experience of embodiment. Furthermore, radical empathy may be achieved without words, generated through being present with the other and open to their expression, voice, affect and style: 'intellectual clarifications follow later' (Heikinen, 2004: 572).

In the next sections I will apply a phenomenological framework to the published qualitative data in exploring the experiences of illness, 'normal' ageing and frailty.

Phenomenological approach to illness

In illness there is disruption of an organised whole rather than 'loss' or 'addition', a qualitative change in which there are transformations not only in the physical self but also in the existential self, in that the various kinds of possibility and projects to which we are receptive are linked and depend upon each other for their intelligibility. Normally, we experience our bodiliness and our lived space with a habitual pre-conscious tacit knowledge which Merleau-Ponty calls *praktagnosia*. Through this we maintain a 'grip' on the world. With the loss of skills through pain or illness, this grip is lost and aspects of the body become foregrounded (moving from disappearance to what Leder terms 'disappearance') in a way that changes 'I can' into 'I no longer can', requiring adjustment if it is not to threaten the self and its projects. The experience of living in a sexist and ageist society can also result in a more routine bodily alienation which has an inhibiting effect on motility and expressiveness and which can magnify the effects of physical changes or problems, including the changes associated with ageing.

Where the usual condition is that of bodily certainty, the bodily doubt that comes with illness or impairment limits concrete plans and generates loss of meaning and felt connection to the world. Illness and limitation disrupts the temporal and spatial horizons of lived possibility which may result in a focus on the present, viewing the future as threatening and uncertain and/or perceiving the past as disconnected from the present and alien, as if belonging to someone else.

Phenomenologically, this estrangement of what was once familiar is captured by the concept of the uncanny or '*unheimlich*' drawing on Heidegger's notion of *unheimlichkeit* or homelessness in the world. Whilst Heidegger sees human life to be one in which one is born into homelessness, in the existential sense which recognises meaning as something created not discovered, this only becomes a medical problem when associated with illness or impairment. It also suggests that the mission of health-care practice and intervention should be not only to 'cure' or ameliorate disease or frailty but also, through devoting attention to being-in-the-world of the patient, to open up possible paths back to homelikeness (although this may be a different 'home' than the state previously experienced as such) (Svenaesus, 2000).

However this focus on disturbance of ordinary embodied structures also requires an account of the positive adjustments that take place and the reconstruction of normality that is equally an experience of (especially chronic) illness. In her 2008 autobiographical account of living

with lung disease, Havi Carel (2008) provides a vivid phenomenological account of this process. She talks about the process of adapting to new limitations of the body, wherein new routines were established and a sense of homelikeness, as well as expanding horizons, crept back in. Yet negative aspects remained, sometimes emerging suddenly when again her body would dys-appear with over-vigorous exercise, or the challenge of unfamiliar streets, for example. A change in her temporal horizons occurred in that her past was gradually severed from her present appearing as fantastical, scarcely believable: 'I held a tennis racket and ran around a court – or did I?' (p. 112). Still, the autobiographical passages of this book are haunted with a sense of loss, of nostalgia for what was, and part of the reason for this is clearly relational, as she is constantly aware that her state of being is not 'normal' for a woman in her prime, for a mother of a young and active child, for a busy University teacher. This experience may of course differ considerably for older people for whom limitations may be both more expected and shared by one's peers (Pound et al., 1998; Wiles et al., 2018).

One of the benefits of such phenomenologically rich accounts is that they can be used to question formal diagnostic categories (Carel, 2016; Ratcliffe, 2012) which may, for example, cover a wide spectrum of lived experiences. So, frailty indices cannot capture the complexity and heterogeneity displayed among older people (Looman et al., 2018), suggesting that phenomenological exploration may also be pursued with a view to inquiring whether a 'different taxonomy or another language are required' (Carel, 2016: 108).

In the next section I turn a phenomenological lens upon the structures of embodied experience which comprise normal ageing.

The phenomenology of 'normal' ageing

Ageing involves a normal experience of 'diminished everyday competence' (Torres & Hammarström, 2006) (DEC) in small or larger ways, from decreased sensory perception, stiffer joints, lesser energy, through to more serious limitations (two-thirds of people over the age of 75 are living with a long term condition (Barnett et al., 2012)) and underpinned by the changes that occur with ageing in all cells, tissues and organs. However, although reserve capacity is lost from major organs, such reserve capacity is far greater than is needed at earlier stages of the lifecourse. Phenomenologically, the changes wrought by ageing on the sensory dimensions, as well as weakened sight and hearing, may include 'disequilibrium, weakness, unsteadiness and pain - with the potential to affect the embodied reality of movement' (Gish and Vrkljan, 2016: 35). However, as every General Household Survey attests, it is normal for older people to rate their health and wellbeing as good despite the co-existence of chronic limiting conditions. As well as the tendency to dissemble or avoid complaint, as noted above, Sidell (1995), points out that diagnosed disease and subjective experiences of either illness or wellbeing do not have a straightforward relationship. Those with illness or frailty diagnoses may feel well and are coping but those with no clear symptoms, conversely, may feel very unwell.

Phenomenology can shed light on this complexity through its concepts of the habitual body and its dis/dys-appearances, bodily intentionality, horizon and mood and its emphasis on lived space as different to objective space. Moreover, as well as decrements, as Gish and Vrkljan put it, 'gerontological phenomenology also sees processes of ageing join with the prereflective and sensual capacity of the body to equip the older body with new modalities and dispositions in later life' (2016: 36). A key aspect of this is the ability of older people to adjust to DEC in their everyday lives (Ågren, 1998; Heikinen, 2000, 2004; Richardson et al., 2014; Torres & Hammarström, 2006; Wiles et al., 2018). In their sample of 21 home-dwelling adults, aged between 75 and 93 (of which the majority were women), Torres and Hammarström found three distinctive approaches to DEC namely (i) that DEC cannot be overcome and must be accommodated to; (ii) that DEC can be

temporarily overcome but eventually will have to be accepted; and (iii) that DEC can neither be overcome nor accepted. Interviews revealed that the first group were managing well and even thriving by turning problems into challenges, or opportunities to grow; they did not dwell on increasing problems in the future but enjoyed the present. Temporal horizons remained open, structured towards projects and goals; there was continuity in terms of lifetime identity; and embodied deficits disappeared in a background gestalt. Receiving help was not (or no longer) problematic, but rather supported part of this ability to go on coping. The slow accommodation combined with advanced age of group (i) in comparison with the rest underpinned the fact that there was no longing for previous activities and indeed some made statements that they preferred *not* to do the activities they had once enjoyed, indicating an existential transition. Group (iii), by contrast, experienced ageing not as normal but as problematic, as if it were illness. Horizons had shrunk, life felt cramped and the need to dwell in the present felt limiting, the gestalt was weighted in favour of loss and dysfunction. Of their life, “it is impoverished”, said one; “I stay home because it is so difficult,” said another (all quotes: 2006: 296–8). The future threatens; “One can start having problems with one’s hearing also and then I’ll be *even* more handicapped”, remarked a woman of 85. The latter had recently lost her vision unexpectedly but others in this group were young-old and thus had had less opportunity to accommodate to these conditions. The transitional group (ii) provided significant insight into how the process of accommodation, of moving from group (iii) to group (i) could proceed. “I was so active and did not want to acknowledge my age,” says 78 year-old Katarina. “But when I got this problem with my legs I became more limited naturally. But I have tried to continue as usual, as much as possible, to make a comeback...” The future is still more threatening for this group and less open as compared to the first group; they purposefully shrink from looking ahead. But the body is more familiar, less an object (alienated) body, though not yet a subject body (Gadow, 1983) when it will again form the tacit ‘from’ structure, from which ones projects are launched (Leder, 1990). Although not an aspect on which the study dwelled, support from neighbours and friends as well as services was important in easing the passage from stage (iii) and gender and class aspects may also impinge. These findings are broadly corroborated by other studies of well-being in the context of challenges in advanced age (sometimes described as ‘resilience’) which include physical, social and personal dimensions, centred on place, and impact on by formal and informal help (see Wiles et al., 2018 for an excellent summary).

Riitta-Liisa Heikkinen’s research (2000, 2004), a rare example of phenomenologically-driven research and an exemplar for its merits, deepens our understanding of these components. She carried out longitudinal research with a number of older people in Finland, whom she interviewed over a ten year period, at ages 80, 85 and 90, by which latter point those who were still alive were all relatively healthy, despite some limiting health conditions, and able still to care for themselves. In this experience of ‘normal’ ageing over time she identified changes in their bodiliness. At age 80 they tried to distance themselves from their symptoms and objectify problematic body parts; at 85 all noted a deeper sort of fatigue. “I didn’t really feel this tiredness until now at this age. All I have to do is sit around for a couple of hours and chat and I gradually get more and more tired” (p. 574). By 90 they had adjusted sufficiently for this bodily change to be a normal backdrop. One 90 year-old told Heikkinen, “You have to learn how to be old” (p. 574). This did not mean that at the age of 90 the embodied state had become straightforwardly unproblematic. Heikkinen notes that for the 85 and 90-year-olds, ‘the experience of a bodily burden is a broader phenomenon than that of illness; it is almost an everyday experience: “Your feet are heavy, you feel tired, you can’t cope with your chores.”’ However, this was acceptable, indeed normal: ‘time and again in their narratives the narrators stressed that they looked upon ageing as an entirely natural process’ (2000: 474).

Phenomenology of frailty

I have prefaced this account of the phenomenology of frailty by a detailed discussion of the phenomenology of ‘normal’ ageing because, contrary to the thrust of medical approaches towards ageing today, I wish particularly to stress the aspects of continuity, as well as explore change across these categories, indicating the dynamic border between the two, together with the heterogeneity of experience contained within both categories. Certainly felt frailty is often the result of disruption at both the physical and social levels that threatens the sense of ‘I can’ in ways similar to that of illness more generally. Also like many illness experiences, as well as the experience of DEC, the conditions that are associated with an objective diagnosis of frailty can be accommodated with time, by repairing old skills as well as building new habits and strengths (including with help and support) and not just once but, in the dynamic conditions of embodied ageing, repeatedly.

During the experience of bodily disruption that leads to felt frailty, bodily movements become foregrounded, impeding bodily motility as taken-for-granted skills have to be relearned as well as new ones acquired. Before this takes place, there is a sense of *unheimlichkeit* of being ‘out of place’ in one’s familiar surroundings. Florence, aged 87, who had fallen, described to Caroline Nicholson et al. (2012) the problems with having to learn how to walk again with a walking frame. She described the way she had to ‘stop and think’, when walking, which was both new and very challenging. 98 year-old Pat described her ontological insecurity, after an injury sustained from a fall threw her off balance: “it’s difficult to describe, but I was looking for trouble all the time...” (2012:1429). Falls and other illnesses thus disrupt *praktagnosia*, leading to the loss of both the habitual body and of ‘grip’ in the world. The immediate aftermath is struggle and possibly anguish such as experienced by Florence who explained how ‘she was brought up to be independent and always on the move, and found her immobility “intolerable” whilst Pat found being housebound “so terrible” as going out and socialising is “when I feel alive” (2012:1428–9; original emphasis). Liz Lloyd et al. (2012:10) note how, for the frail older people in their study, disruption was perceived as a ‘step-change in their age identity’: “It’s a complete reversal of my life,” stated Andrew, 80; “I feel like a fish out of water” Lena, aged 80, reflected. But one’s grip can be restored and the personal and external elements which facilitate this are key in our understanding of the best use of therapeutic interventions and on how frailty can be ameliorated, halted or reversed.

Thus, in a sample of older people aged between 80 and 94 (Mahler and Sarvimaki, 2012), all of whom had experienced falls, certain individuals learnt to cope with them including through courses that taught techniques on how both to fall more safely and to get up afterwards. ‘Brigitte spoke about how to gain balance, pay attention to bodily imbalance and be aware of sensitive bodily situations’ which also helped her view falling as part of ‘normal’ ageing (Mahler and Sarvimaki, 2012: 90). Illona, who had been shocked and upset at falling in the street, trained her muscle strength and mobility and learnt to use a wheeled walker, shifting from a position in which she had resisted it as a ‘symbol of frailty’ to one in which it came to be invested with meanings of independence and empowerment as she took it upon herself to instruct others on how to use it (Mahler and Sarvimaki, 2012). The walker was thus incorporated into her habitual bodily schema allowing Illona to continue her projects and maintain a continuity of self. We can see these as examples (albeit extreme) of what is a universal existential experience, namely the way that subjectivity is ‘demolished and remade by the course of time’ (Merleau-Ponty, 2002: 255). This further suggests that frailty should be seen in terms of a (possibly temporary) disruption of bodiliness, a more severe form of DEC but phenomenologically continuous with it. It is not, that is, an ‘identity’ in the ontological sense of the term and certainly not one with all the terminal associations of the ‘fourth age’.

Relatedly, this making-homelike also involved (re)establishing routines and daily practices necessary for constructing ‘anchorage’, a

sense of continuity, comprising sustaining a place in the immediate world and grounding participants in a 'wider continuity of social relations' (Nicholson et al., 2012: 1429). Older people across several studies were very aware, conversely, of the dangers of not keeping these routines up, however effortful they might at times have felt. 87-year-old Doreen told Nicholson and colleagues that she would love to stay sitting in her chair all day but "You see my friend: she started staying in the chair. And then it was staying in her dressing gown and she seemed to just drop away then; that I sort of think to myself, 'no, you mustn't do it; you've really got to keep on...'" (p. 1429). Maintaining a sense of *heimlichkeit*, including in one's home, is revealed here to be far from a passive practice but indeed effortful and continuous.

This is where mood impacts bodiliness, disrupting ability to adjust to DEC for those with 'objective' frailty symptoms, thus transforming it into something identified by older people as existentially unique. Thus, lived frailty was perceived by older people across a range of studies (eg Nicholson et al., 2012; Schoenborn et al., 2018; Warmoth et al., 2016) as a 'state of mind' and one characterised by 'defeat' and 'the end of the line' (Schoenborn et al., 2018). But by this is meant far more than 'psychological frailty'; 'getting back on one's feet' is both literal and metaphorical (Nicholson et al., 2012: 1428; see also Becker, 1997); it is an all-enveloping mood or mode of being. By contrast, a 90-year-old 'normally' ageing female respondent explained to Heikkinen: "I'm now living with my age. Yes.. I'm not giving up yet. When it [death] comes in due course then that will be that" (2004: 576). What she is expressing here is the intent to live as fully as possible unto death, rather than to succumb to apathy or despair and thus disengage from life, sliding into an intermediate state between life and death, the state sketched out in the comment made by a 77-year-old woman who said of frailty, one is 'easily broken which means possibly if you've almost given up and it wouldn't take too much to make you give up' (2016: 1492) (Warmoth et al., 2016). Similarly, despite her moderately frail classification, Diana, aged 79, did not identify as frail "because I fight against it" (2016: 1492).

What does fighting to retain one's grip involve? Krystal Warmoth and colleagues found three strategies employed by older people: a) by remaining socially engaged; b) by containing limitations, relating them to a particular condition or associating them from a body part, from which they then distance themselves; and c) by comparing self with others whom one considers more frail (a notable contrast to Carel's experience). Additionally, data from a Dutch study (Van der Vorst et al., 2017) suggests that those who resisted frailty had succeeded in keeping their temporal and spatial horizons open compared to those with the same objective health status. Those who reported subjective wellbeing no longer felt a sense of loss in terms of their problems but focused on positive aspects including the aspects of continuity that remained, even where modified or considerably adapted to the new context and indeed were better at adapting to difficulties and keeping active including incorporating aides and new techniques into their bodily repertoire. Similarly they still viewed the future with hope, anticipation and continued ambition. Here, as well as identifying individual factors the researchers corroborated the fact that 'giving up' is often traceable to unmet need in a broad existential, as well as practical and immediate, sense that is in many instances remediable.

Julie Skilbeck's (2014) ethnographic exploration of living with frailty captures the dynamic process of moving into and out of frailty, including the lived experience of uncanniness/*unheimlichkeit*, the loss of bodily certainty and anxiety that results, followed in many cases by repair. Following a fall, certain of her informants were fearful and identified as frail, but with rehabilitation that mood often receded and in the case of Martha, with a combination of willpower and appropriate support, she went from talking about feeling frail and being terrified of tripping, to feeling so much embodied security that she reviewed the original falling experience and no longer felt that it was her own fault but rather attributed it to an 'accident': "I don't feel frail now. I just know it is possible to slip up accidentally" (2014: 174). In such a way

she reestablished continuity of identity between past and present; similarly the future no longer threatened: "So, I just have to watch it. Mind you there's no point in watching it; if it's going to happen it's going to happen" (2014: 174). This is similar to Keen's view of recovering from depression which, he says, 'involves not just the disappearance of a symptom but the reappearance, reinvention, or rediscovery of a self with a past and a future' (1984: 808; quoted in Moustakas, 2011). Vera had had a number of falls and was feeling very vulnerable in the sense not only of present incapacity but fear for the future, including whether she was capable of staying in her home. She was worried about her capacity to manage personal care, especially toileting, and expressed a feeling of frailty, which she linked to a sense of the future as threatening. But towards the end of the study, with support, she had recovered her energy and was far more self-sufficient. She said: "I don't feel frail anymore: I can do a lot. I was able to make myself a cup of tea this morning and I had a bath yesterday. The carers helped me in with the bath chair but I was able to wash myself. And I was singing, and they said, "Who's that singing?". I said, "It's me, haven't you heard me sing before? "And they said, "No.""" (p. 175). Freund suggests that emotion, as a mode of being, "cannot simply be expressed in the language of linear propositionality; that is why poetry, music and art are appropriate ways of expressing feelings' (1990: 459) and in Vera's case, singing expressed engagement with her lifeworld and a return to 'health'.

On the other hand, Skilbeck's example of Keith demonstrates how repair is not always achieved. He began to lose what was already a precarious grip on the world when his close friend died. This friend had visited him on a weekly basis and the loss was also the loss of an already-attenuated thread of connection and engagement with the world. Keith's wife had died three years' previously and a year later his daughter had also died from cancer after which he lost contact with his grand-daughter. He now felt frail: 'That's knocked me back because I could sit and talk to him, have a laugh. Remember things as they used to be... there's nobody.' This loss slid soon into a depression and Keith began to neglect his daily routine. Skilbeck notes, 'Keith was able to continue and to some extent to manage his daily routines; however, he seemed to have lost the motivation to do so' (2014: 179). Falls followed; hospital admittance was followed by a visit to an intermediate care unit. In their final interview, he confessed: "I have no appetite... I stay in bed unless I eat, I'm too tired. Since before Christmas, it's been a toll. I've lost my confidence. I've gone downhill... I've been trying to pull myself round but I've no interest" (2014: 180).

There is certainly a sense in which frailty can indicate a closeness to death; what Caroline Nicholson and colleagues describe as a 'drawn out, uncertain and dwindling process of dying' (2012: 1427). At the same time, however, Keith's example sounds a warning note as to the inevitability of that process and urges sensitivity to the role played in this by loss of meaning that can accumulate through small, overlooked and possibly remediable deficits.

Discussion and concluding remarks

Supporting people like Keith and Vera out of frailty requires understanding of, and sensitivity to, the numerous factors in their world, medical and social, that contribute to a problematic bodily disappearance and sense of *unheimlichkeit* which together can lead to despair and defeat which is understood by older people themselves as frailty. In research involving interviews and focus groups with older people, carried out by consultants Britain Thinks for Age UK and the BGS, the researchers noted that old people conceived of their independence in terms of various stages which the researchers then operationalised into a 'scale of independence'. This ranged from stage 1 (full independence) to stage 5 (entire loss of independence) (Britain Thinks, 2015). While three stages would all be objectively classed as frailty, these were distinguished for the old people in terms of degrees of wellbeing. While stage 3 is 'struggling' or 'feeling frustrated' stage 4 is 'feeling vulnerable'

or 'not coping' and stage 5 is 'giving up'. Little in the way of objective physical differences separate these stages, which are also compatible with the experience of normal ageing (Sidell, 1995; Torres & Hammarström, 2006). Yet it is clearly on preventing the move from stages 3–5 that healthcare professionals will need to focus, both in the context of frailty and more generally, and for that an understanding of unique lived experience is crucial.

To be most helpful and effective, services and health care professionals also need to recognise that frailty, and embodiment in general in old age, is a mix of strength and weaknesses combined. Although it is easier to order phenomena in neat categories with clear divisions, if as a society we are prepared to recognise the normalcy of ageing, as well as own the value of this stage in the lifecourse, then paradox and messiness has to be engaged with in a psychologically more sophisticated strategy than the current norm, as it is precisely the failure to recognise normal ageing that older people are challenging when they deny their 'frailty' status. The autobiographical writings of Florida Scott-Maxwell (1968), composed when she was in her eighties, present a sustained account of advanced old age as an increase in embodied energy, growth and interpersonal connections combined with the constraints of weakness, illness and isolation. Indeed, she felt, good health and vitality was enjoyed because it is embedded in the midst of frailty and pain (which is comparable to the experience of happiness for those suffering from long-term depression: Keen, 1984). This draws attention to the fact that an old person's intentionality, sense of being at home in the world and grip can all flourish in ways that younger people may overlook or, in a failure of imaginative or radical empathy, dismiss.

As this paper has demonstrated, phenomenological methods enable identification of a rich variety of experiences currently subsumed within a unitary diagnostic category, including frailty as a dynamic experience in which one can both feel frail and recover from this in different contexts, as well as highlighting how a variety of factors, personal and external, may facilitate the latter. Preceding this with a phenomenological exploration of the lived experience of 'normal' ageing has demonstrated the embodied structures common to health, illness and frailty in old age. Health services research has similarly noted the enormous heterogeneity found within the category of frailty, declaring that, therefore, "the" frail older person does not exist' and finding at least 5 groups or classes within that classification displaying a vast 'constellation of problems' Looman et al., (2018) which a phenomenological approach is well-placed to unpick. The paper has shown how ageing more generally involves both the loss of embodied habits and capacities and the gaining of new ones. That these can be learnt and developed in later life challenges the view of ageing as featuring only loss and decline. This account thus troubles the distinction between frailty and normal ageing and in turn suggests the possibility of refining clinical nosology.

However, this paper represents an early stage in this aim and more research is needed to explore the multiple kinds of frailty experiences, their link to older people's ascribed and other characteristics, as well as the support that can best be utilised in different contexts to help restore a sense of homelikeness, which is health itself (Svenaesus, 2000). Research conceived and designed from within a phenomenological perspective will be especially helpful in this task. An approach that starts from the first-person perspective can contribute much to the clinical aim of avoiding unnecessary hospitalisations and other adverse events especially if, informed by radical empathy, it avoids problematising ageing embodiment per se. This goes well beyond the current clinical emphasis on improving muscular and bone strength and nutritional health, useful though all these components undoubtedly are; furthermore, anticipating and preventing risk within geriatric medicine will only be possible with an appreciation not just of objective conditions but of lived space and time. Indeed key physiological terms can all be enriched adding, for example, to the concept of biological homeostasis a social homeostasis and seeing the 'tipping point' as lived as well as phenotypical where multiple failures, with social support, can be

forestalled from becoming the chain reaction characteristic of pathology. But where phenomenology differs from increasingly scientific approaches in medicine is in viewing frailty as comprising strengths as well as weaknesses and conceiving good health as inextricably bound up with limitations, especially but not only in old age. Here, geriatricians claim to 'know it when I see it', actually employs an intuitive phenomenology which could be encouraged alongside more 'objective' or structured assessments using new frailty technologies (Korenvain et al., 2018). Finally, in all these ways, by countering the approach that separates the frail from the rest this approach seeks to challenge the establishment of frailty on the one hand and successful ageing on the other as marking the outer limits of (what is increasingly becoming) the only legitimate framework through which old age can be understood today.

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