



The emergence of multimorbidity as a matter of concern: a critical review

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Abstract Multimorbidity is considered one of the greatest emerging challenges for contemporary health care systems. However, the meaning of the term ‘multimorbidity’ is not straightforward. Despite many attempts to clarify the definition and its measurement, the concept remains elusive. Still, academic interest in the study of multimorbidity has grown exponentially in the past ten years. In this paper, we trace the emergence of multimorbidity as a ‘matter of concern’ within health care research, exploring what has been called ‘the multimorbidity epidemic’ in the context of changing disease categories. We analyse how multimorbidity as a concept lays bare some major unresolved challenges within contemporary care services and summons up traditional primary care ideals of holistic, person-centred care. However, we argue that the current focus on the measurement and the identification of disease clusters falls short in contributing to better care for people who live with multiple long-term conditions now. Instead, we propose a novel understanding of ‘multimorbidity’ as an experience that manifests through people’s navigations of care infrastructures. To study this experience of multimorbidity, we discuss the potential of social science approaches that focus on ‘living well’ with illness.

Keywords Multimorbidity · Multiple chronic conditions · Comorbidity · Social navigation · Person-centred care

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Introduction

In the past ten years, there has been an “explosion of interest” (Xu et al. 2017, p. 67) in multimorbidity within various academic disciplines. Multimorbidity has been referred to as one of the greatest emerging challenges for health care systems today and in the future (Pearson-Stuttard et al. 2019). However, the meaning of the term ‘multimorbidity’ remains contested; indeed, the concept conjures up many different meanings, including, though not restricted to:

- the co-existence of multiple age-related health conditions in older people, associated with (and by implication a direct result of) an ageing world population;
- the early onset and high prevalence of complex mental and physical chronic health conditions exacerbated by adverse social conditions. This version of multimorbidity foregrounds the ways in which illness and social adversity perpetuate one another;
- the co-existence, in one person, of two or more chronic conditions whose needs are not fully met by care systems which are organised around a ‘single disease’ model. Under this view multimorbidity is not so much a fixed phenomenon ‘out there’, but serves, as Lefèvre and colleagues argue “as an avatar for the fundamental, recurrent problems of modern medicine and the organization-of-care” (Lefèvre et al. 2014, p. 138).

Several systematic reviews (e.g., Busija et al. 2019; Larkin et al. 2020; Xu et al. 2017; Rosbach and Andersen 2017) and even a systematic review of systematic reviews (Johnston et al. 2019) have explored the definition, measurement, prevalence, burden, and patient experience of multimorbidity. These reviews draw similar ‘conclusions’, namely that conclusions *cannot* be drawn unless the term multimorbidity is more clearly defined. For example, Johnston (2019, p. 182) recommends that researchers should identify which particular diseases fall within the definition. Notwithstanding the potential value of identifying common disease clusters, this approach risks paradoxically depriving ‘multimorbidity’ of “any possible nosological independence” (Lefèvre et al. 2014, p. 308). Moreover, one systematic review (Stirland et al. 2020) found that there are already at least 35 indices of multimorbidity each with different components and outcomes, which highlights the difficulty of narrowing the term to specific disease combinations. Ho et al (2021), in a recent systematic review examining variation in the measuring of multimorbidity, recommend that a core set of conditions be included in all measures, to improve comparability and reproducibility of research in the multimorbidity field. The question of what will be gained through efforts to tidy up the definitional ‘mess’ concealed within the multimorbidity phenomenon remains relatively unexplored although this has become the focus of considerable targeted research efforts within life sciences.

The emergence of multimorbidity as a matter of concern that is fuelling great academic interest calls up several questions. Why, for one, is the co-occurrence of



multiple illnesses such a problem; what *kind* of problem is it and *whose* problem is it? Is the co-occurrence of diseases really a new phenomenon, and if it is not, why is it often presented as a pressing and new problem that is characteristic of our historical time?

A daunting amount of literature is thus already available on the topic of multimorbidity, covering both qualitative and quantitative approaches. Although authors generally recognise that this body of work is too heterogeneous to synthesise systematically, they usually blame this on a lack of common definitions or standard indices. However, we propose that the difficulty of finding coherence in multimorbidity research is down to differences entrenched at a level deeper than the lack of common definitions. As Greenhalgh et al (2009, p. 729) found in their review of literature on the Electronic Patient Record, multimorbidity is a concept that covers “multiple research traditions with different underlying philosophical assumptions and methodological approaches”. We concur with their view that the best way to find sense and meaning in a “swamp” of resources on a certain topic is to adopt a narrative approach which can trace the multiple meanings a concept takes on and thus clarify why it somehow remains stubbornly elusive.

To clarify a seemingly incommensurable body of literature, Greenhalgh et al (2005) propose an approach to meta-narratives that builds on Kuhn’s notions of scientific paradigms to explicitly expose and make visible the incommensurability between different research traditions on a single topic. We embarked on this review adopting a similar approach, but it soon became clear that multimorbidity has challenged many researchers to step outside of their research traditions and methodologies and forge collaborations. We therefore decided to trace multimorbidity’s histor(icit)y and meaning in health research and take, in Greenhalgh et al’s (2005, p 17) words, “the unfolding storyline” of multimorbidity studies over time as our main unit of analysis.

We rejected the ‘traditional’ systematic review method. Several systematic reviews on the topic already exist and have so far been unable to provide fruitful syntheses due to the heterogeneity in the definition and study of multimorbidity. Our approach has enabled us to systematically trace multimorbidity storylines across social science, public health and primary care research sources, unlimited by disciplinary terrain. Instead of limiting ourselves to a narrowed-down body of work or disciplinary terrain, we looked for literature through exploratory methods (browsing, asking colleagues) followed by snowballing (searching references of references and using citation-tracking databases) to identify key sources. We drew on a variety of sources to help us contextualise the literature we encountered while placing “the burden of theory on the recording, not on the specific shape that is recorded” (Latour 1996, p. 374). This unstructured method enabled us to make sense of an increasingly complex and heterogeneous body of literature. Multimorbidity is a fuzzy notion: in order to understand its emergence fully, it was important not to just focus on this stand-alone concept, but also to understand the rise of chronic illness as a public health concern, and the increasing difficulties faced by underfunded and overstretched primary care systems in dealing with complexity.

The following research questions guided our search: (1) how has the multimorbidity concept emerged as a matter of concern within health care and health care



research; (2) what does its emergence tell us about the characteristics of and tensions within contemporary systems of care? (3) Looking at the future, how might we move beyond the current scientific endeavour to pin down an inherently fuzzy phenomenon, to study multimorbidity in a way that is meaningful to people living with multiple health conditions?

First, we will explore what has been called ‘the multimorbidity epidemic’ (Adan et al. 2020) in the context of changing disease categories. Second, we will analyse multimorbidity as a concept that lays bare some major challenges within the organisation of contemporary care services and recalls many of the traditional primary care ideals of holistic, person-centred care. Third, we call into question the need for ever-more precise definitions and measurements of multimorbidity. Instead, we argue that a focus on ‘chronic living’ is vital for research that aims to understand how people might live well with multiple long-term conditions. We propose the concept of ‘social navigation’, as first developed by Henrik Vigh (2009), as an empirical approach to multimorbidity research that allows for multiplicity brings into sharper focus the ways in which multimorbidity plays out in the in the day-to-day experiences of patients.

Multimorbidity: a new matter of concern?

Multimorbidity is often framed as related primarily to an ageing population (e.g., Afshar et al. 2015; Nguyen et al. 2020; Vasiliadis et al. 2021), an unintentional side effect of the triumphs of biomedicine during the last century (e.g., Bähler et al. 2015; Fortin et al. 2012; Boyd and Fortin 2010). This common narrative holds that ameliorated hygienic circumstances and the development of new biomedical techniques have dramatically improved life expectancies around the globe. This in turn leads to a larger proportion of older people with multiple, often age-related, chronic conditions (Omran 2005), burdening patients and care systems alike, and generating new challenges for public health to address. This compelling narrative is empirically underpinned by epidemiological studies that do indeed show a rising prevalence of chronic illness (e.g., Fleming et al. 2005; Wang et al 2016) and multimorbidity (van den Akker et al. 1998; Wu and Green 2000; Divo et al. 2014; Kingston et al. 2018). However, it is instructive to examine some of the assumptions which underpin this taken-for-granted explanation of the multimorbidity phenomenon.

The first, and perhaps most basic question that needs answering is ‘how is multimorbidity measured?’ As it stands there is no agreement on the definition of multimorbidity. The most commonly accepted definition is “the co-occurrence of two or more chronic health conditions”. Consequently, the type and number of diseases included within the definition vary greatly across studies. The lack of consistency in definitions leads to widely diverging prevalence estimates, from 16% to 58% in UK studies, for example (Hajat and Stein 2018). Public health researchers working in the multimorbidity field are very aware of this problem and recognise the importance of clearly stating what is measured and which disease categories are included in the study. Mostly, researchers include common chronic mental and physical conditions



such as diabetes, cardiovascular diseases, anxiety, and depression, but across studies, the number of morbidities included might range from two to 285 (Ho et al. 2021).

However, clearly stating what is measured does not definitively solve the ‘measurement’ problem. Rather it raises a second problem: disease categories are not stable, but subject to constant change. Changes in how certain diseases are defined are sometimes more responsible for apparent shifts in prevalence over time than actual changes in the prevalence of pathology within the population. Important for multimorbidity studies is that the term “chronic illness” in its current use is a relatively new concept in health care. The rapid increase in the use of this concept is often said to be due to the fact that more people are now living into old age with long-term health conditions. However, what is striking about epidemiological data on chronic illness is that prevalence does not just increase with age, but that *age-specific prevalence* also increases rapidly over time (McGrail et al. 2016). This means either that we are dealing with a “true pandemic of chronic disease, especially pronounced in elderly people”; or we are witnessing the result of a “diagnostic creep, people are now diagnosed with a chronic disease who would not have been so a decade or two ago” (McGrail et al. 2016, p. 1).

Sociologist David Armstrong (2014) has provided evidence for this second hypothesis based on his analysis of reports published in JAMA since 1883. He concludes that the rise of chronic illness is not so much linked to an actual increase in the prevalence of long-term disease, but rather due to the medicalisation of old age from the 1950s onwards. Armstrong argues that conditions that were previously seen as the result of a ‘normal’ process of ageing and degeneration, such as arteriosclerosis and cardiovascular disorders, were, from the 1950s onwards, pathologised and brought under medical control. In the first half of the 20th century, causes of death such as ‘old age’, ‘senility’, and ‘atrophy’ were still commonly registered; from the 70s onwards, almost no one is registered as dying of natural causes. Armstrong’s analysis points towards “a major cultural shift: emphasis on chronic disease has been about rejecting attitudes of hopelessness, inevitability, and neglect applied to a variety of conditions, including those of old people, and transforming them into targets of intervention and amelioration” (Weisz 2014, p. 9).

Diagnostic thresholds for disease categories have also changed over time, often as a result of guidelines prepared by expert panels. In the U.S., Moynihan (2016) investigated recent changes to the definitions of 14 common conditions, including hypertension, depression, and Alzheimer’s disease. He found that:

Of 16 publications from the panels, only one proposed a narrower definition, for five the impacts were unclear, and 10 proposed an expanded definition – pre-diseases were created, thresholds were lowered, or diagnostic processes changed to enable earlier diagnosis. In no case did a panel rigorously investigate and report on the potential danger that some people may be caught unnecessarily by the newly widened definitions. Among the panels that disclosed competing interests, 75% of panel members had multiple financial ties to a median of seven drug companies each. These members were paid by companies for activities like speaking, consulting, advising, or researching. This is in direct contrast to recommendations from organisations like the US Institute of



Medicine for more independence among those who write guidelines. (Moynihan 2016, p. 30)

In the U.S., for example, the shift in the diagnostic threshold for hypertension from 160/100 to 140/90 mmHg in 2003 resulted in a 35% increase in the number of North-Americans fulfilling the new diagnostic criteria (Martin et al. 2014). In the UK, similarly, the current definition of prediabetes means that 1 in 3 adults have this condition (Mainous et al. 2014). The diagnostic creep responsible for calls of ‘epidemics’ of mental health conditions such as anxiety, depression, and ADHD in Europe and the U.K. has also been thoroughly described (e.g., Rose 2006; Helén 2007). Still, the diagnosis and treatment (with medication) of common mental illness is steadily rising. Between 1990 and 2000, the overall psychiatric drug market increased by 126% in Europe and 638% in the U.S. (Rose 2006). In both the U.K. and the U.S., the largest growth was seen in the use of antidepressants, for which prescriptions overall rose by 200% in that same decade. It is difficult to know whether and to what extent we are really witnessing an epidemic of mental illness, and how changing practices of diagnosis and treatment coupled with increased marketing of pharmaceuticals are reflected in the epidemiological account.

Heath argues that diagnostic expansion is the result of “a toxic combination of vested interest and good intentions” (Heath 2013). On the one hand, it is symptomatic of what Beck (1992) has called ‘the risk society’, in which people have become less tolerant of potential bad outcomes. In medical culture this plays out in heightened interest and investments in prevention and screening. Patients themselves are likewise encouraged to take up this cultural shift regarding the role of health in providing a more secure future, one expression of this being the increasing promotion and use of health monitoring technology (Lupton 2014). On the other hand, pharmaceutical companies go to great lengths to advertise their products and create financial and professional interests for physicians to prescribe them, for example by involving them in clinical trials, sponsoring medical education and providing gifts. In a recent systematic review, pharmaceutical industries’ marketing and promotion strategies are identified as some of the most influential factors influencing physicians’ prescribing decisions (Davari et al. 2018, pp. 799–800).

The consequences of broadening disease categories are by no means trivial since more diagnoses lead to an increased burden of treatment and risks overdiagnosis and overtreatment. Overdiagnosis refers to a diagnosis that does not produce a net benefit for the diagnosed person (Carter et al. 2015), is a waste of resources for the patient as well as for the health care system, creates unnecessary worry and distress, and can lead to polypharmacy. Moreover, “we are labelling more and more healthy people as sick and building bigger potential markets for those selling medicines” (Moynihan 2016, p. 30). This has important consequences for distributive justice within the health system and can result in *undertreatment*: financial resources, time and attention shift away from those who are most severely affected by ill health towards those who are relatively healthy; under- and overtreatment are two sides of the same coin (see also Heath 2013).

By placing the rise of multimorbidity in the context of ‘diagnostic creep’, it becomes clear that claims of a ‘multimorbidity epidemic’ cannot be taken at face



value. Instead, the rise in multimorbidity prevalence must be seen in light of the expanding domain of health care. This perspective raises profound moral questions and demands careful reflection on the limits as well as the potential of medicine to support healthy living. In an era where more and more people are considered ‘at-risk’ of illness, even when symptoms are not present (yet), the Hippocratic axiom of ‘primum non nocere’ (first do no harm) becomes an increasingly complex concern.

Multimorbidity and the limits of contemporary care services

Multimorbidity may not be an entirely new phenomenon, but there is increasing concern that contemporary care services are not configured to adequately deal with patients with multimorbidity. Sinnott et al (2013) found that GPs experience the care for patients with multimorbidity as challenging on many levels, and patients themselves experience high ‘burdens of treatment’ (May et al. 2014) because they have to constantly navigate various systems of care and adhere to a variety of treatment plans (Rosbach and Andersen 2017; Van Merode et al. 2018). Additionally, people with multiple chronic conditions are especially vulnerable to the detrimental effects of too much medicine. In a recent study of a health centre in “one of the most deprived areas” of the UK, Ecks (2021) found that patients are often harmed by what he calls ‘polyiatrogenesis’, the unintended but nevertheless harmful effects of many uncoordinated interventions. Through case studies of people with physical and mental multimorbidities, he argues that treatments targeted specifically on one disease often culminate in complex effects, and risk overtreatment and polypharmacy. Ecks (2021, p. 14) concludes that participants in his study “are multimorbid in their 30s and 40s not because they do not get treated, but because they get treated.”

However, the story of polypharmacy and overtreatment is more complex than Ecks’ conclusion may lead us to believe. There is a strong awareness within the health research community of the dangers of overtreatment and the need for less intrusive medicine and de-prescribing (e.g., BMJ’s *Too Much Medicine* initiative; May et al. 2009; Heath 2014; Swinglehurst and Fudge 2017; ABIM’s *Choosing Wisely* campaign). However, several factors complicate the move towards holistic treatment. Fear is one such factor. Iona Heath (2014, p. 2) describes how “doctors work every day in fear of missing a serious diagnosis and precipitating an avoidable tragedy for one of their patients.” She argues that doctors are learning to be afraid of uncertainty, and to battle this uncertainty lean on an increasing number of tests and treatments for people whose problems cannot always be brought under control through medical care.

There is a clear consensus among multimorbidity researchers that primary care professionals are best positioned to manage patients with multimorbidity. This is not surprising since primary care traditionally adheres to values such as the delivery of person-centred, comprehensive, and ongoing care. It is especially preoccupied with patients who have ‘complex’ needs and the development of complex interventions in the real world. Doctors with responsibility for one condition or body system may not have the generalist, holistic overview needed to support patients with complex care



needs (Treadwell and McCartney 2016), whereas GPs are well-positioned to deliver continuous, horizontal healthcare (Watt 2017).

Iona Heath suggests that the general practitioner may be particularly well placed to safeguard “the patient from the too ready interpretation of illness as disease” (1995, p. 28), a ‘guardianship’ orientation to providing personal medical care that may be particularly important in the context of already existing multimorbidity. However, this potential may depend heavily on the conditions of professional practice. Primary care in the U.K., as in many international contexts (e.g., Shi 2012; Bakker and Groenewegen 2009), has become increasingly driven by market-logics and characterised by escalating health policy pressure to conform to processes of standardisation, bureaucratisation, and cost-effectiveness. Furthermore, health services in recent decades have been pushed towards an ever more scientific-bureaucratic form of medicine (Harrison 2002). An example was the introduction in 2004 of Quality Outcomes Framework (QOF), a points-based, pay-for-performance system through which general practices receive payments for meeting a set of predetermined targets framed as indicators of quality. The QOF places an economic value on patients’ biomarkers, which has been argued to commodify patients’ bodies, fragment care, heighten the role for information technology and shift practitioners towards a more biomedical form of medical care (Checkland and Harrison 2010; Norman et al. 2016).

This presents special challenges to professionals dealing with the complexities of multimorbidity. Modern science is characterised by a need for predictability and objectivity; attained through rigorous protocols and set rules; a process that has been termed the ‘colonisation of the future’ by sociologist Giddens (1999; see also Luhmann et al. 2002). However, increasing complexity will lead to increased uncertainty and unattainability of objectivity, and thus, greater need for autonomous practical wisdom. As argued by Champy (2018, p. e2660), “the claim for objectivity in an uncertain world is an illusion that prevents handling problems properly”. Although in medical practice set rules (such as protocols, guidelines) have an important function it is important that professionals feel the liberty to deviate from a rule when it appears ill-suited for a singular case. In a system where medical professionals are financially rewarded for meeting certain outcomes it is questionable whether professionals are still able to exercise the necessary ‘practical wisdom’ when confronted with complexity.

Developments towards bureaucratisation and cost-effectiveness are compounded even further by fiscal challenges faced since the global recession in 2008, with primary care systems in Europe and the UK experiencing significant financial disinvestment (Majeed 2012; Stuckler et al. 2017), a process disproportionately affecting primary care in deprived areas (Fisher et al. 2020). A recent longitudinal U.K. study demonstrates the stubborn persistence of Tudor Hart’s inverse care law (1971), or a decrease in healthcare delivery with social disadvantage, within general practice in recent years (Nussbaum et al. 2021). Perhaps this is reflected in the statistic that patients living in more deprived areas are prescribed more medicine than people in less deprived areas, even in contexts of similar rates of primary care attendance (Hodgson et al. 2020), which Hodgson and colleagues suggest may be an indicator that a primary care system under significant pressure may be vulnerable



to contributing *adversely* to mechanisms of overmedicalisation, overtreatment and polypharmacy, with GPs unable to deliver on their role as ‘guardian’ against over-investigation and overtreatment (Heath 1995). Critical public health theorists have argued that the high prevalence of chronic physical and mental illness in deprived neighbourhoods may be due to the ‘medicalisation of poverty’, a process whereby resources are spent to “address healthcare needs brought on by poverty instead of providing for the tangible needs of the poor before illness results”, thus [...] treating “the symptom, not the problem” (Shepherd and Wilson 2018, p. 536) and simultaneously locating responsibility for ill health with the individual and their ‘choices’ (Viens 2019).

Primary care’s increased focus on standardised guidelines, computerised protocols and checklists backed by evidence derived primarily from randomised control trials creates a potential weakness in the system for patients with multimorbidity, who, importantly, in the U.K. account for most of the GP consultations and hospital admissions (Cassell et al. 2018). Treatment guidelines and protocols are typically based on single diseases, reflecting the disease-based orientation of most medical science, and also the interests of the pharmaceutical industry which drives research into medicines that act in a disease-specific way (Lakoff 2008). Hence, most RCTs only include ‘ideal-type’ patients with single diseases; patients who are multimorbid or considered ‘complex’ in any other way are generally excluded from clinical trials. This system perpetuates the risk of iatrogenic polypharmacy and high burdens of treatment. If ‘best practice’ treatment guidelines, developed for single diseases are simply added up for people with multiple conditions—a practice which pay-for-performance schemes encourage—high treatment burdens and overtreatment may be the unintentional and potentially harmful consequence (Hughes et al. 2013).

Studying the social navigation of multimorbidity.

The study and management of multimorbidity call for new approaches. As an object of study, the concept diffuses borders and requires new boundary-work: long-established disease categories, and the treatment guidelines accompanying them, no longer hold ground. Nor does a clean-cut separation between the physical, social, and mental realm, given that one in three patients with multimorbidity has a coexisting mental health condition (Salisbury et al. 2018) and the onset of multimorbidity happens 10–15 years earlier in socially deprived areas (Barnett et al. 2012). So far, there has been a tendency within multimorbidity research to focus on the measurement and the identification of disease clusters and pathways, without it being at all clear how this might serve people who live with multiple long-term conditions now. Similarly, while the argument for person-centred and holistic approaches for people with multimorbidity is tirelessly repeated, it is not so obvious what these approaches might look like in practice. The need for a better understanding of what care services for people with multiple health conditions would ideally entail is emphasised by the fact that interventions for this patient population have so far not been very effective (Salisbury et al. 2018; Smith et al. 2016).



The difficulty in studying multimorbidity, as we outlined in the first section of this paper, is that it subsumes a wide range of possible disease combinations, and, by implication therefore also a heterogeneous patient population with highly varying illness experiences. This makes multimorbidity a hard phenomenon to work with for life and social scientists alike. The often-proposed solution for this is to limit the research focus to commonly co-occurring diseases, instead of multimorbidity as a more general concept. Syndemics theory, for example, coined by medical anthropologist Merrill Singer (1994) examines why certain diseases cluster, pathways through which they interact biologically in individuals and within populations, and how social environments, especially conditions of social inequality and injustice, contribute to disease clustering and interaction (Singer et al. 2017, p. 941). The syndemic model is thus designed to investigate fixed, common clusters of specific illnesses within a certain context. Although this theory successfully draws attention to the fact that political, social and economic factors contribute to the clustering of certain diseases, the biosocial model that is inherent in syndemics studies has an important pitfall, in that it reduces poverty and injustices to the effects these have on the body: “syndemic analysis pathologizes the populations around which these social and biological pathologies are said to coalesce” (Sangaramoorthy and Benton 2021, p. 2).

Moreover, there is an assumption in the syndemics model that people with the same conditions will have similar experiences that can be categorised into common patterns. This approach unintentionally reifies current disease categories, while people with multiple conditions often experience symptoms that are hard to classify, and suffer in part, *because* of the way diseases are currently categorised and treated. Many people with multiple health conditions experience a range of symptoms that spill over from the physical into the mental realm and vice versa, often as a result of life-long conditions of adversity. Additionally, a single condition can have very different impacts depending on the economic and social context of the person who lives with it (Montesi and Calestani 2021).

We argue that the conceptual strength of ‘multimorbidity’ resides exactly in its difficulty to be pinned down. As such, ‘multimorbidity’ takes our attention away from specific body parts and organs (or even collections of organs or ‘systems’). Instead, it draws our focus to how the body operates as a whole. We therefore propose a novel understanding of multimorbidity: not as something that exists as a unified phenomenon, in the bodies of people, but as an experience that manifests through the discrepancy between medical policy and life-as-lived, brought to the fore by people’s attempts to bridge fissured care systems. Through this understanding of people’s experiences of multimorbidity in daily life, researchers may learn new notions of the body that correspond better with reality, as entities that cannot be separated from their environments. Indeed, the few multimorbidity studies that have so far approached the topic from a daily practice perspective clearly exposed the mismatch between health policy and people’s experiences of multimorbidity beyond the biomedical domain. A recent study focusing on older people prescribed ten or more items of medication, shows how much of the management of illness goes on at home (Swinglehurst and Fudge 2021). The authors found that patients do much hidden ‘work’ to manage polypharmacy, and often find creative ways to deal with the demands of their health condition. Another study looking into the experiences of



older Pakistani patients with multimorbidity (Sultan and Swinglehurst 2021) found how self-management programs, often promoted as ‘best practice’ for multimorbidity, fall short in their framing of patients as isolated individuals. Instead, for these participants, health is a matter that is deeply linked to family and faith.

To understand ‘multimorbidity’ as an experience that manifests through people’s navigations of bureaucratic and fractured care infrastructures, we argue that a focus on ‘chronic living’ (Wahlberg 2017) is vital. Although illness is, in many ways, unavoidable, care can either “lead to, shape, alleviate or complicate chronicity” (Montesi and Calestani 2021, p. 8). Insight into what daily chronic living in the context of multiple health conditions looks like, puts us in a better position to advocate sustainable care infrastructures that can indeed alleviate chronicity. ‘Chronic living’ does not necessarily always refer to long-term living with illness. People may be diagnosed with diseases without experiencing any symptoms. These ‘invisible’ diseases still have consequences: they produce anxiety and require work, but they may not produce any bodily experiences of suffering. This potential discrepancy corresponds with the classic disease vs. illness divide developed in qualitative health research (e.g., Kleinman 1988), whereby disease refers to biomedical concerns with biologic structure and functioning, and illness indicates human experiences of symptoms and suffering. However, Mol (2002) has suggested that this distinction has the pitfall of forcing social scientists out of the realm of the body. In ‘The Body Multiple’, Mol argues that we can respond to this by foregrounding practicalities, materialities and events, to make ‘disease’ part of what is done in practice. Indeed, when attending to the multiple practices involved in living with multimorbidity, we can see how both the clinical notion of long-term disease—including the life-long monitoring and management that it requires—as well as the everyday experience of ‘living with illness’ are equally relevant to the meaning of ‘chronic living’. In clinical settings, a condition can be understood as chronic because there is a continuous risk of developing symptoms, whereas in a person’s life there may be long symptom-less stretches where the only reminder of the diagnosis is the medication people take or the diet they are recommended to follow. Chronic living in many cases refers not (just) to living with symptoms, but to the everyday management of health conditions through monitoring, medicines, diet, and exercise. In some cases, symptoms may only become noticeable when people don’t have the resources to manage healthy lives. Examples might include situations of social adversity or political instability, when chronic conditions can become acute in their complications (Manderson and Smith-Morris 2010).

In understanding multimorbidity as an experience that manifests in people’s daily navigations of systems of care, it becomes clear that all aspects connected to the issue of multimorbidity discussed in this paper have real repercussions for people’s experience of it. The medicalisation of old age, polypharmacy, the specialisation of medicine and the bureaucratic management of multiple health conditions by care services all form part of living with long-term health conditions. As Manderson and Wahlberg (2020, p. 431) point out, chronic living consists of more than just failing biologies: it is shaped by political economies and ecologies that determine families’ life conditions, care networks, and access to healthcare. Chronic living requires people to readjust and learn how to live *well* with illness in the long run (Wahlberg



2017). This asks for a different frame of mind in how we understand disease: not as a temporary matter, that a medical fix can cure, but rather as a “chronic crisis” (Vigh 2008). Crisis is normally understood as an isolated period of time in which a life becomes derailed, however, for people living with chronic illness crisis can become “endemic rather than episodic” (Vigh 2008, p. 5). The crisis here thus becomes the context in which people continue their daily lives. Within this context of chronic crisis, people must find new ways of relating to their environment; of occupying their ecological niches after they have become ill.

We propose to use the concept of ‘social navigation’ (Vigh 2009) as an analytical tool to study how people negotiate chronic living in the context of multimorbidity. More broadly, the concept of navigation has been used to describe how people with multiple health conditions find their way through interactions with various systems of care (Ørtenblad et al. 2018); in this way, it functions as a ‘metaphor for practice’ (Vigh 2009, 419). However, Vigh’s concept of ‘social navigation’ reminds us that to navigate “literally means ‘to sail’, and “thus defines a special form of movement: that is, the way we move in a moving environment” (2009, p. 420). This way, the concept brings forth the image of a landscape in continual change: fluid and unsettled, motion within motion. As an analytical framework, it helps us see “how people move and manage within situations of social flux and change”, thus highlighting and integrating the interactivity of people and practices. This opens the possibility of joining perspectives on how care infrastructures changes, for example through new professional configurations in primary care and initiatives such as social prescribing, and how patients move within this changing system.

Everyday life is not static, rather, it is an uncertain site of difficulties, hardships, and triumphs. In contrast to concepts such as ‘landscape’ or ‘site’, a dense temporal dimension to analysis is added by looking at navigations: not only do people need to adapt to the immediate changes in their present surroundings but they are also continuously involved in imagining their prospective position (2009, p. 425). Importantly, exploring ‘social navigations’ has the potential to highlight agency while at the same time allowing that.

not everything can be navigated and not all situations are navigable precisely because navigation is not just a question of drawing a line between two points on a map: the movement of the social environment influences our every endeavour. [...] It highlights the limits of the power embedded in our capacity to define and control our social worlds. In other words, no matter what the level of power, we are never completely free to move as we want, and rather than being vulgarly voluntaristic, navigation actually points our attention to the fact that we move in relation to the push and pulls, influence and imperatives, of social forces. (Vigh 2009, p. 431)

The novelty of the concept of social navigations resides exactly in its ability to position its focus on how people shape their lives within certain political, economic and social constraints. This is crucial to a nuanced understanding of people’s everyday experiences with illness, and some ethnographic studies on experiences of people with single long-term conditions have already been able to show the relevance of such an integrated approach. Dokumaci (2017), for example, found that disability



can become a source of vitality when people creatively overcome the challenges that living illness impose on them. In her video-ethnography, Dokumaci (2017) shows the example of the “mismatch” between a knife that needs effort to cut with it and the painful hands of a participant. The participant solves this mismatch by taking the knife out of the combination and replacing it with her teeth, which also afford cutting, without the need to use her fingers. Dokumaci calls these solutions acts of “micro-activism” and argues that by paying close attention to the daily practices of people living with illness or disability, much can be learned about this creative potential. On the other hand, people’s control over their movements in a medicalised world are still limited, as these are significantly shaped by temporal logics that accompany health interventions, as Benton et al. (2017) argue in the case of HIV/AIDS. Health policies and funding shift regularly, thus also changing the type of medicines and treatments available to people with health conditions. Also, in many countries time spent on waiting lists to access certain treatments forms a large part of what it means to live with multiple conditions, which arguably forestalls people’s motivations to find their own terms on which they might be able to live with illness. It’s important to advocate against unhelpful care infrastructures, because, as Vigh (2008, p. 11) argues, “though we may talk about the normalisation of crisis we should not confuse normalisation and routinisation with indifference: crisis, when it is chronic, may become normal in the sense that it is what there is most, but it does not become normal in the sense that this is how things should be.”

There is an importance in attending to everyday life that goes beyond mere description. Living with multimorbidity implies living with “diseases that remain” (Pols 2013). In her study of an online community of people living with COPD, Pols (2013) shows that people with multiple long-term health conditions often need to translate medical knowledge in order to use it in their daily lives and try out different strategies to coordinate health care aims with other aims in life. In contrast to medical knowledge, patient knowledge is “aimed at living daily life with disease or disability in a good way. What this good entails is highly dependent on the contexts and the aims of individual patients. [...] as well as on their use of medical technology and scientific knowledge” (Pols 2013, p. 83). Supporting the development of this type of knowledge, aimed at living well with disease, “requires- at least for part of the time- letting go of the dream of cure and its paradoxical appeal to demand attention and money for something that cannot be done away with.” The inclusion of knowledge gained by patient experience into policy and practice could prove highly beneficial to supporting efficient self-management of multiple chronic conditions, shaped by and for the need of real-live patients (Hughes 2019).

Studying multimorbidity through the concept of ‘social navigation’ can move us beyond attempts to pin down the concept through ever-more precise definitions and measurements, an endeavour that has cost much effort but has not returned many results over the past ten years. Instead of locating multimorbidity as a problem in a person’s body, we can instead think of it as an experience that exposes the limits of diagnostic categories and disease-based care. As such, studying multimorbidity through a focus on daily life pushes researchers to move beyond ‘lumping’ people together into one study population and freeze-framing their “illness experience” into predictable patterns. By following patients through their navigations of



ever-changing systems of care, we can gain a better understanding of where we can intervene in the organisation of care to lower burdens of treatment and avoid over-treatment and futile care.

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Declarations

Conflict of interest The authors have no competing interests to declare.

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