Living with multimorbidity: medical and lay healthcare approaches

Multimorbidity is rapidly becoming the norm rather than the exception in healthcare. Research on this issue is increasing and this review discusses a selection of clinical and social science literature. The focus is on understanding the complexity of the lived experience of multimorbidity and how this is presented in clinical encounters, drawing on examples of arthritis within a multimorbidity context. Taking into account the biophysical, psychological, social and cultural factors that shape multimorbidity this paper calls for a re-conceptualization of the concept, allowing a more dynamic and holistic approach.

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Prevalence estimates of multimorbidity in primary care range from 12.9% (in participants aged over 18 years) to 95.1% (in participants aged 65 and older) [1]. Notwithstanding the variation in estimates, it has become increasingly clear that the majority of people over 45 years of age live with more than one condition [2,3]. This poses challenges, not only for the individual and their social network, but also for the health and social care system and society at large.

In this paper we will begin with defining multimorbidity, provide a brief overview of the clinical literature and discuss some implications for healthcare. The main focus of the paper will be on the literature concerned with the lived experience of multimorbidity, drawing on a number of theoretical concepts from the social sciences. While mental health needs to be included in considerations of multimorbidity, we are not able to address this within the confines of this paper. Our attention is predominantly on physical ill health as a result of coexisting conditions, drawing on examples of people living with rheumatoid or osteoarthritis (RA and OA) and other conditions. We will conclude the review with suggestions about re-conceptu-alizing multimorbidity taking into account both clinical and patient perspectives.

Clinical perspectives

Medical specialists tend to use the term comorbidity to indicate their focus on an index condition with other coexisting conditions being considered in relation to the index condition. In contrast, the concept of multimorbidity is seen as more useful to generalists such as General Practitioners (GPs) or geriatricians because it is defined as 'the coexistence of two or more long-term conditions in an individual' [4]. No primacy is given to any one condition and therefore a more holistic, interactional approach can be adopted.

For clinicians the diagnosis and treatment of people with multimorbidity has become increasingly important, and a recent systematic review [5] examined a range of complex interventions in primary and community settings. They reported a number of issues, including the need to clearly identify the group of people with multimorbidity, to target individuals with specific risk factors who may benefit most from tailored interventions, and to develop

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cost-effective interventions that deliver specific outcomes for patients.

Beyond prevalence studies, epidemiological literature has also investigated associations between multimorbidity, patient outcomes and service resource utilization. In this regard, multimorbidity is associated with increased mortality rates [6,7] and is inversely related to health-related quality of life. A large number of studies have identified multimorbidity as a major source of expenditure within healthcare systems which are oriented toward a single disease model of illness. Multimorbidity has been shown to be a valid predictor of hospital inpatient costs [8] and is associated with both unplanned admissions to hospital [9] and increased length of hospitalization [10]. People living with multimorbidity are more likely to consult their doctor [11], and costs associated with prescribed medications also increase with multimorbidity [12]. More generally, studies into the total costs of healthcare provision identify that the costs of general healthcare increase dramatically among people living with more than one chronic illness [13,14].

The rise of clinical guidelines has promoted consistency in treatment by applying best available evidence to specific conditions. Yet, at the same time they cause problems in terms of their focus on one (set of) condition(s) [15,16]. The rationale for single disease guidelines is increasingly being questioned by researchers and health policy professionals as not fully capturing the patient within context. Evidence exists to suggest that the implementation of existing clinical guidelines may be detrimental to the care of people with multimorbidity [17]. In particular, strict adherence to clinical guidelines has been associated with undesirable and potentially harmful polypharmacy [18]. Furthermore, in order to cover the wide range of clinical problems a multitude of guidelines have been published and when treating patients with multiple morbidities the clinician is faced with the difficulty of managing several guidelines alongside each other that may be contradictory or hard to combine. The need to develop a guideline-type approach for multimorbidity has been called for to counter the tendency within consultations to discuss conditions individually, rather than focusing on how they are experienced as part of the totality of problems 'in the patient.' Hughes *et al.* suggest that clinical guidelines should cross-reference one another systematically, to include specific common multimorbid vignettes, and for a change in the ways that clinical guidelines are evidenced and used in practice [16]. Apart from the application of clinical expertise to individual patients no new model has yet emerged, but the UK National Institute of Health and Clinical Excellence has started to consider alternatives to the one condition approach.

Defining multimorbidity in medical terms as the coexistence of more than one condition tends to lead to a focus on 'having' rather than 'living with' multiple conditions. It also places emphasis on adverse effects on people's lives. We do not argue that medical attention is unimportant, yet, concentrating on the disease aspects, in other words, the deficits, marginalizes what people can do despite illness, namely what assets remain. The clinical model also often focuses on 'frailty' in older people with multimorbidity [19] and clinicians state that they can easily distinguish the frail from the non-frail older person. However, sociologists argue that frailty is socially constructed [20]. Gilleard and Higgs argue that 'frailty' has replaced infirmity as a term signifying personal marginality and vulnerability. The frail so constituted has few or no such validated identities or narratives of their selves that are empowering. Instead, frailty has been rearticulated as a social imaginary foreshadowing the feared future of a decrepit fourth age [21]. Older people themselves rarely use the label of frailty to describe their own health and illness experience. While the symptoms of the conditions that comprise their multimorbidity are real, frailty is a social construct that has implications for the delivery of services in which the 'frail' older person tends to be relatively uninvolved and social and emotional experiences may be overlooked [20].

Self-management approaches underpinned by individual-oriented behavior change theories have received increased attention in that they are seen to benefit people with chronic illness (and multimorbidity). Clinicians have welcomed these approaches for patients with chronic conditions, considering them as a useful adjunct to clinical interventions. Yet, recent critiques have argued that living with chronic illness and adopting self-management practices are complex social processes that need to be considered alongside individual coping mechanisms, and thus calling for a wider-ranging perspective [22]. We will return to this issue later.

Patient perspectives

The literature on patient perspectives on multimorbidity is still small, but has slowly increased specifically drawing on sociological theories. One strand is based on studies of chronic illness, in particular RA, which have highlighted the dual meaning of living with such conditions: first, the consequences of chronic illness, such as reduction in physical mobility or the presence of pain; and second, the significance of a chronic illness such as RA, in terms of identity which may be affected through loss of paid employment or impaired ability to socialize [23]. These two concepts of consequence and significance are relevant to the experience

of multimorbidity as the complex interplay between conditions can have a major impact on people's lives. A key tension lies in the differential importance given to each concept by clinicians and patients: essentially, the clinical perspective sees multimorbidity as important in terms of (functional) 'health consequences.' This is underlined by the concern with health 'outcomes' in current healthcare (e.g., English Quality and Outcomes Framework for primary care). Patients attach importance to both concepts, and perhaps the lower attention paid to 'significance' in therapeutic encounters reduces the focus on 'person-centeredness' in clinical practice.

Understanding impact on people's lives requires reference to a further theoretical perspective that can throw light on how multimorbidity is interpreted in everyday life. Paterson's 'shifting perspectives' model argues against the trajectory model of chronic illness (illness depicted as a phased process wherein the individual follows a predictable trajectory), which is also reflected in geriatric practice. Rather, according to this model:

"Living with chronic illness is an on-going, continually shifting process in which people experience a complex dialectic between themselves and their "world"… As the reality of the illness experience and its personal and social context changes, the people's perspectives shift in the degree to which illness is in the foreground or the background of their "world"" [24].

The lay experience of multimorbidity might be considered in terms similar to those employed by Paterson. In particular, the critique of the trajectory model of chronic illness may be extended toward the biomedical principles of multimorbidity. First, multimorbidity as a model considered in additive terms whereby illness is defined through the delineation and enumeration of discrete conditions requires nuancing from the perspective of those who live with multiple conditions. A number of factors need to be taken into account, such as the nature and lay understanding of the conditions, perceived seriousness, the extent to which symptoms and treatments interfere with everyday life, whether conditions are experienced separately or as a whole, and primacy at any one point in time. Consequently, it can be argued that multimorbidity is experienced in a holistic manner where the different illnesses interact in a manner unique to an individual and together shape their life.

Second, multimorbidity as premised upon a mode of concurrency that is clearly defined and a-temporal may be questioned. Grime, Richardson and Ong [25] demonstrate in their study of people living with multiple conditions including OA, that one condition may be foregrounded because of, for example, in the words of

participant, an exacerbation of symptoms or an unexpected change in reactions to normal treatment:

"…if it's a thing [a joint pain] that you know you've got to live with, then I think you've got to carry on regardless. But, like I say, if a sudden pain comes on then it is a warning, what's going on like, and you can see the doctor" (Brian, early 1960s) [25].

The dynamic nature of prioritizing a particular condition in multimorbidity has been further emphasized by Cheraghi-Sohi et al. [26] who carried out a secondary analysis of four studies of people with OA and other conditions. Their analysis suggests that illness priorities shift according to social context, clinical interactions and the ability to control symptoms. They cite the words of a patient:

"It's not been a straightforward thing for me … like, one problem to get over and then another one pops up. I spend more time sorting that out." (ID 29) [26].

Conceptualizing multimorbidity in this dynamic and fluctuating manner is important in a number of ways and we will discuss its relevance in relation to self-management, social identity across the life course and sociocultural context.

Self-management

Existing literature concerning the patient experience of multimorbidity has been shaped, to a large degree, by wider UK policy imperatives concerning the management of long-term conditions in primary care. In particular, the drive toward patient self-management as a means of chronic illness management has also influenced studies of the ways in which people with multimorbidity self-manage their illnesses. Self-management is considered a means of involving patients and wider family members in issues of choice and decision making [27] together with the clinicians providing their care. It is further seen as a mode of healthcare delivery that is less costly, and as means of working toward easing the financial pressures posed by an ageing population living with increasing levels of chronic illness. These tenets have been subject to a number of trenchant critiques which question both the political impetus behind self-management and also its underlying evidence base [28–30]. However, despite such criticism, self-management continues to be a policy priority.

The rise of self-management has been discussed critically in relation to its reliance on psychological theories. Ong et al. [22] note that 'the rise of cognitive approaches to understanding behavior and emotion have increasingly focused interest and behavior change technologies on the intrapsychic processes of belief and attitude formation, cognitive styles and mental models' (page 228). This, the authors argue, should

be met by an affirmation of the role of the social, with self-management being recognized as an inherently social practice because people continually try to make sense of their condition and draw on various coping mechanisms, and strategies that they have developed over time. This may include their social networks and/or professional care and the recursive relationship between individuals and services contextualizes self-management.

One of the key issues concerns the 'hard work of self-management' which Thorne *et al.* [31] describe as coping with social interactions, managing one's lifestyle such as making choices about how to maintain health and well-being, managing health encounters and medication regimes, and outcomes may vary. Self-management involves a complex process of deciding what is meaningful in life, and weighing up expert advice against lay experience. Consequently, self-management has to be understood within an individual's overall life context, desires and aspirations, and Townsend *et al.* [32] further emphasize that illness management work is guided by moral principles. This is explained by Clarke and Bennett [33] who studied 35 older people who had on average six conditions, with the most commonly reported ones being arthritis, back problems and heart disease. They contend that individuals with multimorbidity not only manage the practicalities of illness, but also attend to self-management in moral terms, namely that they work toward the 'moral responsibility' of preventing additional chronic conditions and functional loss.

The moral dimension of self-management will be shaped by patient's wider social, cultural and political circumstances. Clarke and Bennett [33] describe the gendered nature of morality; male participants often strive to accomplish the masculine ideals of control and invulnerability whereas female participants emphasize feminine norms of selflessness and the care of others. This perspective highlights the place of additional frameworks of sense making (in this instance morality). An appreciation of such factors offers the potential for more insightful interpretations of the experience of living with multimorbidity and what influences people's choices.

Self-managing more than one condition heightens the sense of complexity because interactions with healthcare professionals and following regimens are multiplied. Being a patient with multiple conditions may become a full-time occupation at the expense of maintaining one's normal life, and self-management can then be considered as oppressive rather than empowering. In this way the policy imperative ends up in tension with individual quality of life.

Social identity

Turning attention to Bury's study of people with RA and his concept of meaning as significance [23] multimorbidity can cause fundamental changes in people's lives that affect their social identity and sense of self. As a result of their illnesses, many people will be confronted by stark choices such as whether or not to stay in work, pursuing leisure activities and particular lifestyles. This has adverse implications for people's sense of identity.

Studies have shown that individuals expend considerable effort in maintaining a sense of self. Reeve *et al.* [34] argue that managing the physical impact of chronic conditions demands individual creative capacity in remaining motivated and resilient. Mars *et al.* [35] show that people attempt to retain autonomy through continuous readjustment of their self-perceptions and the limitations that conditions pose upon them in their interaction with the world. This persistent pattern of adjustment and adaptation is termed 'emergent present' by Griffiths *et al.* [36]. In their study of people with chronic joint pain Ong *et al.* [37] talk about implicit, organic and experiential learning coexisting with explicit, evaluative accounts of the way in which individuals amend activities or lifestyles. They provide the following example quotation:

"I just used a bandage, took loads of Ibuprofen, loads of anti-inflammatory and half a bottle of wine every night (laughter). I mean, there's no point ruining the holiday completely, is there? (ID 5888) [37].

Thus, gradual and sometimes imperceptible changes are made to maintain one's identity, and thus continuity in a sense of self can be preserved. The examples from the literature reflect a diverse set of conditions, but the argument about the importance of maintaining and redefining one's social identity is generic and cross-cutting.

Sociocultural context

People's sense of self is formed within their sociocultural context, and with regards to considering the experience of chronic illness the notions of social networks and social resources have received considerable attention in the sociological literature. Research in this area has considered the role of social networks in the provision of social support, and also the impact of chronic illness upon social relationships. In this sense, the place of family and friends has been considered in Bury's distinction between meaning as consequence, and meaning as significance: the role of family and friends is understood both in terms of the practical and emotional assistance provided by others, but also in terms of the impact of illness upon social relationships [38,39].

Corbin and Strauss [40] identify the place of social networks and social resources as essential to the accomplishment of the three lines of 'illness work' (illness work, everyday life work and biographical work). Similar to studies of social support the role of others appears to include instrumental, emotional and informational assistance. Corbin and Strauss deliver an account of the substantial role of spouses, family members and friends in accomplishing the 'work' involved in living with chronic illness.

However, practices of support and cooperation during illness have also been identified as problematic for those concerned, and a number of studies have identified supportive relationships as a source of ambiguity and strain [39]. Individuals may feel that the balance of their relationships turns unequal in that they are receiving more than they can give. This may lead to feelings of indebtedness and obligations, while on the part of those giving support their 'love' may become perceived as 'labor' [41]. Bury provides a broader analysis of potential tensions by focusing on uncertain changes and unpredictable futures based on his research on people with RA:

"The experience of chronic illness involves testing structures of support and risking meanings within the practical constraints of home and work. Relationships do not guarantee particular responses, indeed it is the response that shapes the relationships; meanings change as they are tested and altered as they are put at risk. Individuals and their families cannot be entirely sure what the event of such an illness means or will mean for the future; meanings are fashioned in the flux of change, as events unfold" [23].

It can be argued that in the case of multimorbidity these fluctuations are multiplied and interactions between different conditions and their attendant phases difficult to anticipate. The role of social networks and social support becomes even more complex. Consequently, social networks cannot be understood simply as a resource for the management of illness at home, but are also fundamental in shaping meaning as significance. Multimorbidity is recognized as posing a threat to previously valued social roles and identities; yet family, friends and loved ones are central to the ways in which this meaning is fashioned and reformed.

Recently, more interest has focused on the role of individuals' social networks in terms of chronic illness self-management. In this body of literature social networks are identified increasingly as a resource to aid self-management and patient outcomes. For example, Rosland and Piette argue that:

"As a result of the growing gap between the need for self-care support and existing resources, family members are increasingly recognized as important allies in the care of chronically ill patients, and the last decade has seen a rapid growth of self-management programmes that include family members" [42].

As stated earlier, the involvement of informal social networks in self-management support is believed to deliver more acceptable and efficacious care from a patient perspective, and increased economic efficiency in the management of long-term conditions. Vassilev *et al.* [43] similarly identify social networks as central to the ways in which people living with chronic illness self-manage their conditions. The authors argue that self-management must recognize the role of community and social networks alongside an individual's own efforts. Rogers *et al.* explicitly state that:

"The translation and implementation of a self-care agenda in contemporary health and social context needs to acknowledge and incorporate the resources and networks operating in patients' domestic and social environments and everyday lives [44]".

In a review into the role of family members in self-management, Gallant *et al.* note the potential for family members to both facilitate and hinder the efforts of individuals with chronic illness. In summarizing findings, the authors identify various ways in which family members affect self-management in a positive sense:

"…direct help with medications, offering medication reminders, cooking healthy meals, following a similar diet, monitoring one's diet, accommodating dietary needs, exercising with, playing an active role during doctor's visits, providing transportation to doctor's visits, sharing illness-related information, acting as a liaison with the doctor, talking about shared situations, offering understanding, and motivating older adults to follow their prescribed regimen" [45].

However, in contrast, the authors also identify the various ways that family members might hinder self-management:

"Not cooking meals that followed dietary guidelines, following a diet with no restrictions, not accommodating dietary needs, tempting them with forbidden foods, discouraging physical activity, giving unwanted advice, engaging in depressing talk, and not understanding the reality of living with a chronic illness… being (overly) protective" [45].

These studies demonstrate that social relationships are no simple panacea: social relationships may function in ambivalent, even pernicious ways. More detailed sociological analysis needs to be developed because it is important to understand how people living with multimorbidity experience the receipt of social resources during illness, and to explore how such supportive practices are considered meaningful by those in receipt of support.

A deficit or asset model of multimorbidity?

Contemporary health policy and public health approaches have embraced an asset model. A recent UK government paper 'Vision for adult social care: capable communities and active citizens' [46] emphasizes the notion that individuals are not isolated consumers of care, but rather, are connected members of social groups. These social groups are understood in terms of their capacity to affect the care and outcomes of individuals. Individuals are conceived as 'active citizens' rather than passive recipients of care, and 'capable communities' as a source of potential resources. In parallel, emerging models of healthcare service have developed asset-based approaches. These approaches may signify a paradigm shift in policy, public health and clinical practice as they seek to identify individual and community resources or 'assets' that may be built upon in order to affect health outcomes. Sir Michael Marmot puts the link between social connectedness and health succinctly:

"The health and wellbeing of people is heavily influenced by their local community and social networks. Those networks and greater social capital provide a source of resilience. The extent to which people can participate and have control over their lives makes a critical contribution to psychosocial wellbeing and to health. Taking an asset-based approach at a local level fosters greater local confidence and self-esteem for people and communities" [47].

In applying this line of thinking to multimorbidity, recent studies have shown that the aspirations of people with multimorbidity are aimed at seeing themselves as living well, despite illness. They discuss wanting to maintain valued activities, engaging in mutually beneficial relationships, fulfilling significant social roles and staying connected with their social networks [25,48–49]. Thus, people talk about adjusting to new realities, and they 'normalize' certain ailments as part of the life course, for example, joint pain as being associated with ageing. Often new identities, such as becoming a grandparent, provide opportunities for redefining oneself as making a valuable contribution (looking after grandchildren) and gaining enjoyment in the face of multimorbidity. This connection with others and being engaged in reciprocal relationships confers psychological and social health benefits, helping individuals to cope with adversity (i.e., multimorbidity).

As the ageing population will continue to rise the recognition of multimorbidity will remain a policy and clinical priority. Clinicians will not be able to avoid managing people more holistically, taking into account their personal assets and social context, if they are to meet public health targets and respond to the drive for health improvement and quality.

Conclusion

The literature on multimorbidity is still evolving, and the social sciences have an important contribution to make to the field. This selective review has highlighted a number of issues – which are relevant to arthritis – that can be summarized as follows: first, most healthcare systems are oriented toward a single disease model (exemplified by guidelines such as the NICE OA guidelines). This results in an 'additive' approach to multimorbidity making it difficult for both clinicians and patients to consider the complexity of regimens and the everyday consequences of living with multiple conditions. Particularly, with regard to OA in older people this tends to be experienced embedded within a complex of other conditions. In their therapeutic encounters generalists such as GPs are thus presented with the totality of multimorbidity, and the application of separate clinical guidelines becomes a complicated balancing act. Patients may at times foreground one condition over another, yet tend to experience the overall interplay between illnesses and their combined impact on everyday life and identity. We maintain the value of diagnosis and treatment of separate conditions but within a patient's lived context, thus taking into account how people (re)define themselves, how they interact with their social networks, what social resources they can call upon, and how they see the balance between wellness and illness. The implications for service design will be considerable as this will genuinely put the patient at the center, requiring separate specialists to communicate and coordinate their regimens at the level of the individual.

Second, Clemence and Seamark's study of GP referral behavior mention that sometimes patients are referred because GPs do not feel they can offer suitable treatment [50]. People with multimorbidity may be at risk of such referrals if they are perceived to be too difficult to manage because of complexity, or when it includes OA in older people GPs often regard this as untreatable 'wear and tear.' The growing realization of the necessity to develop a type of guideline suitable for multimorbidity could help to alleviate this problem, and allow for an approach that enhances patients' quality of life. However, it needs to address the question as to how to take account of social identity and sociocultural context alongside biomedical considerations.

Finally, shifting the focus from a deficit to an asset model raises a number of interrelated issues: at the point of consultation patients seek professional advice and support because they feel unwell or in pain. If clinicians emphasize an individual's assets they run the risk that patients feel that they are not taken seriously, or that a burden is imposed upon them by having to seek out social support. At the same time, an asset-based

approach can help people to focus on what they can do despite ill health, thus maintaining valued activities and foregrounding wellness. This is a difficult balance to achieve and it is, as yet, not clear how this model translates into clinical practice.

Despite the above uncertainties we feel that the literature to date provides a more nuanced understanding of multimorbidity: clinical perspectives, and in particular those of generalists, highlight that current practice falls short in addressing the interactions between coexisting conditions. Healthcare systems have insufficiently kept up with the reality that the majority of patients do not live with single conditions, which tends to be the case for older people with OA, and thus one-dimensional guideline development needs to be rethought. Social science in particular draws attention to the contextualized experience of multimorbidity, arguing that this is shaped by the interplay of biophysical, psychological, social and cultural factors. The way in which individuals live with multimorbidity is variable across the life course, and depends on the personal and social assets that people can draw upon. Facilitating a dialog between the clinical and social perspectives will lead to a more patient-centered and holistic approach to helping people who live with multiple morbidities.

Future perspective

The growing ageing population and medical advances mean that multimorbidity will continue to increase and thus new approaches to dealing with this issue need to be developed. New integrated multimorbidity guidelines should be created taking into account best clinical evidence and patient experiences of living with multimorbidity. Balancing biophysical considerations with psychological, social and cultural aspects will be crucial for a more holistic treatment. Multidisciplinary and multiagency responses to complex need are likely to lead to improved outcomes. We have highlighted these issues in the context of older people living with multimorbidity; however, future research must also address multimorbidity in younger patient populations.

Executive summary

- It has been suggested that clinical guidelines should cross-reference one another systematically, to include specific common multimorbid vignettes, and a change in the ways that clinical guidelines are evidenced and used in practice has been advocated.
- From a patient's perspective it can be argued that multimorbidity is experienced in a holistic manner where the different illnesses interact in a constantly changing way and together shape an individual's life.
- It is important to understand how people who live with multimorbidity experience the receipt of social resources during illness, and to explore how such supportive practices are considered meaningful by recipients.
- Taking an asset-based rather than deficit-based approach is important to support people with multimorbidity so that they can focus on wellness and any dynamic changes over the life course.
- The dialog between clinical and patient perspectives needs to become more sophisticated in order to achieve a holistic approach to multimorbidity.

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