

Primary care practitioner and patient understanding of the concepts of multimorbidity and self-management: A qualitative study

SAGE Open Medicine
I: 2050312113510001
© The Author(s) 2013
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/2050312113510001
smo.sagepub.com


Cassandra Kenning,^{1,2} Louise Fisher,¹ Penny Bee,^{2,3} Peter Bower^{1,2}
and Peter Coventry^{2,4}

Abstract

Objectives: The aim of this article is to offer insight into how professionals and patients understand and experience multimorbidity and how these accounts differ, and how they affect attitudes and engagement with self-management.

Methods: Semi-structured interviews with 20 primary healthcare practitioners and 20 patients with at least 2 long-term conditions (including coronary heart disease, diabetes, osteoarthritis, chronic obstructive pulmonary disease and depression). Thematic analysis was used, and themes were identified using an open-coding method.

Results: Practitioners associated multimorbidity with complexity and uncertainty in the clinic, leading to emotional strain and 'heart sink'. Patient accounts differed. Some described multimorbidity as problematic when it exacerbated their symptoms and caused emotional and psychological strain. Others did not perceive multimorbidity as problematic. Self-management was seen by practitioners and patients to be a key element of managing multiple conditions, but drivers for prompting and engaging in self-management differed between patients and practitioners.

Conclusion: This study suggests that recommendations for clinical practice for multimorbid patients should take into account the gap in perceptions between practitioner and patients about experiences of multimorbidity. Not least, practice would need to reflect the tension between practitioners' and patients' accounts about the role and benefits of self-management in the presence of multimorbidity.

Keywords

Multimorbidity, patient views, practitioner views, primary care, self-management

Introduction

A number of studies show that older patients with long-term conditions generally have more than one condition^{1,2} (often referred to as multimorbidity). People with multimorbidity are predominately seen in primary care, and prevalence is set to increase. In the United States, 60 million people have multimorbidity, expecting to rise to 81 million by 2020,³ and about two-thirds of total US health-care spending may be devoted to these patients.⁴ It is estimated that around 58% of patients attending general practice in the United Kingdom have multimorbidity and that they account for around 78% of all consultations.⁴ People with multiple long-term health conditions were responsible for the greatest burden of disease in most Organisation for Economic Co-operation and Development (OECD) countries (34 countries who signed the Convention on the OECD) in 2011, and their cost and prevalence will increase in the future as populations age.⁵

Current descriptions of multimorbidity tend to use a count or additive model whereby multimorbidity is construed as a state arising from the coexistence of two or more long-term health conditions.⁶ However, conceptualising multimorbidity

¹NIHR School for Primary Care Research, Centre for Primary Care, Institute of Population Health, University of Manchester, Manchester, UK

²Manchester Academic Health Science Centre (MAHSC), University of Manchester, Manchester, UK

³School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK

⁴NIHR Collaboration for Applied Health Research and Care for Greater Manchester (GM-CLAHRC), University of Manchester, Manchester, UK

Corresponding author:

Peter Coventry, Centre for Primary Care, Institute of Population Health, The University of Manchester, 6th Floor, Williamson Building, Oxford Road, Manchester M13 9PL, UK.
Email: peter.a.coventry@manchester.ac.uk

this way does not take into account the differentiated nature of multimorbidity,⁷ the differences between related and unrelated conditions, synergistic or antagonistic conditions, or variation in the impact of multimorbidity on the functional capacity of the individual. Multimorbidity may also have an impact on individual conditions, or lead to new complications arising from multimorbidity itself.⁸

Despite multimorbidity increasingly becoming the norm rather than the exception,⁹ services of National Health Service (NHS) are generally not organised around the needs of patients with multimorbidity.¹⁰ In high income countries with ageing populations and shrinking health budgets, there are growing financial pressures to manage increasing numbers of multimorbid patients more effectively and efficiently.¹¹ The use of disease-specific guidelines is aimed at improving care (including self-management) for patients with long-term conditions, but these guidelines are generally not aimed at patients with multimorbidity.⁹ Use of single disease-based guidelines to treat multimorbidity may lead to burdensome and inappropriate treatment.¹²

It has been suggested that health services, especially primary care, cannot continue to be organised around single conditions and that policy and practice need to be reconfigured to meet the challenge posed by multimorbidity.^{1,9} To understand how services might be more effectively delivered to cope with this growing problem, first, we need to understand in more detail how practitioners and patients conceptualise multimorbidity and how they understand the impact on important aspects of care such as self-management. The aim of this article is to offer insight into these issues and describe the implications for the development and delivery of new models of care.

Methods

This study was nested within a prospective cohort study examining engagement in and predictors of self-management in multimorbidity. The cohort study surveyed 1500 patients with at least two of five exemplar conditions: coronary heart disease, diabetes, osteoarthritis, chronic obstructive pulmonary disease and depression. These exemplar conditions were selected because they are highly prevalent in primary care populations, have varied symptomatology, and present patients and practitioners with different treatment and management challenges. Patients were identified from the disease registers of four general practices in Greater Manchester. A total of 20 patients were selected from 222 patients who responded to the survey, indicating that they would like to be considered for interview. Patients were purposively sampled on number and type of long-term conditions, age, gender and postcode deprivation score. This was to ensure that we recruited a varied group of patients who shared key demographic and clinical characteristics of interest. Four patients were unobtainable or unavailable for

Table 1. Patient characteristics.

ID	Age	Gender	Conditions	Deprivation quintile
P1	68	F	OA, CHD, Dep	2
P2	76	M	COPD, CHD, Dep	4
P3	57	F	OA, CHD	1
P4	58	M	CHD, Dep	5
P5	58	F	DM, CHD	3
P6	88	M	COPD, OA, CHD	2
P7	54	M	DM, OA, Dep	3
P8	67	M	DM, CHD	2
P9	76	F	DM, COPD, CHD, Dep	3
P10	68	M	OA, CHD, Dep	4
P11	76	M	OA, CHD	2
P12	57	F	DM, OA	4
P13	77	F	OA, CHD	2
P14	65	F	DM, COPD, OA, Dep	5
P15	52	M	DM, OA, Dep	3
P16	58	F	Asthma, DM	5
P17	63	F	DM, Dep	1
P18	76	F	COPD, CHD	2
P19	66	M	COPD, CHD	3
P20	58	F	DM, Dep	1

F: female; M: male; OA: osteoarthritis; CHD: coronary heart disease; COPD: chronic obstructive pulmonary disease; DM: diabetes; Dep: depression.

Deprivation quintile: 1 = least deprived, 5 = most deprived.

interview and were replaced with patients who had similar characteristics (e.g. age, gender and number of conditions). Practitioners (n = 15) were initially recruited from the practices taking part in the survey and the remainder from three other practices using snowball sampling. Practitioners were purposively sampled on deprivation (taken from the general practitioner (GP) practice postcode), practitioner role (e.g. partner/salaried GP/nurse) and gender. Tables 1 and 2 show the individual characteristics of each of the interview participants. Table 3 shows a summary of the patient sample characteristics.

Patient interviews were focussed around exploring their experiences of living with multiple long-term conditions, their understanding of self-management and its role in their health management, including eliciting accounts of their experience with healthcare services and supported self-management programmes. The term 'multimorbidity' was not used in the patient interviews. Instead, patients were asked to describe the impact of their health conditions on their daily routines and on their ability to effectively manage their health (Appendix 1). Practitioner interviews focussed on exploring their experiences of working with patients with multimorbidity and how it impacted on their clinical work, their experiences of promoting self-management and their perceptions of how self-management was regarded by patients, as well as on their knowledge of and experiences with supported self-management programmes (Appendix 2). An initial pilot interview was carried

Table 2. Practitioner characteristics.

ID	Practice number	Deprivation quintile	Role	Gender	Years qualified
DR1	1	4	GP partner	M	30
DR2	3	3	GP partner	F	21
DR3	1	4	Salaried GP	F	12
DR4	1	4	GP partner	F	17
DR5	1	4	GP partner	F	8
DR6	2	3	GP partner	F	30
DR7	5	1	GP partner	M	16
DR8	4	2	Salaried GP	M	11
DR9	6	1	GP partner	F	23
DR10	1	4	Trainee GP	M	5
DR11	4	2	Trainee GP	F	5
DR12	4	2	GP partner	M	20
DR13	5	1	GP partner	M	16
DR14	4	2	GP partner	M	36
DR15	5	1	GP partner	F	23
DR16	7	5	Trainee GP	F	5
PN1	1	4	Practice nurse	F	21
PN2	4	2	Practice nurse	F	27
PN3	1	4	Healthcare assistant	F	2
PN4	2	3	Practice nurse	F	10

GP: general practitioner; M: male; F: female.

Deprivation quintile: 1 = least deprived, 5 = most deprived.

Table 3. Patient sample.

Demographic	% or M \pm SD
Female	55%
Age (years)	66 \pm 10
White ethnicity	100%
Number of exemplar conditions	2.5 \pm 0.7
Index of multiple deprivation	24 \pm 17 ^a

SD: standard deviation.

Mean score of 24 lies within the third quintile (18.86–28.70), indicating moderate deprivation.

^aRange from 5.39–66.68; a higher score indicates higher levels of deprivation.

out by each of the interviewers (C.K. and L.F.). Sample recruitment continued until data saturation was reached, and no new themes emerged from the data.

All interviews were audio-recorded with consent and fully transcribed. Interviews lasted between 30 and 57 min (mean 38 min) for practitioners and between 10 and 72 min (mean 37 min) for patients. Field notes were made following the completion of each interview and reread for the purposes of data familiarisation. Analysis was conducted according to the constant comparative method,¹³ whereby analysis was carried out concurrently with data collection so that emerging issues could be iteratively explored. Development of conceptual themes was inductive. Following data familiarisation, emerging themes were organised into a theoretical framework.¹⁴ Transcripts were then indexed against this initial coding and checked to ensure

that there were no significant omissions prior to framework refinement, data charting and synthesis. Themes were constantly compared within and across cases, paying particular attention to negative cases and possible reasons for differences.

Analysis was carried out by four researchers from different backgrounds (general practice, health services research and health psychology) to increase trustworthiness of analysis.¹⁵ Transcripts were analysed independently and coded by hand; emerging themes were discussed until consensus was achieved, and a coding framework that included higher level themes and relevant data was assembled in Microsoft Excel. Each transcript was analysed individually and then in groups, with the healthcare professional transcripts analysed separately from the patient transcripts but with comparisons made across data sets. Quotes are used to illustrate key themes. (*Participant codes: DR = GP, PN = practice nurse, P = patient; Key to conditions: OA = osteoarthritis, CHD = coronary heart disease, COPD = chronic obstructive pulmonary disease, DM = diabetes, Dep = depression*).

Ethical approval was granted by Greater Manchester North Ethics Committee on 12/09/2011 (ref.: 11/NW/0563).

Results

Practitioner's experiences of multimorbidity

Practitioners identified and characterised multimorbidity by drawing on narratives about how encounters with patients

with multimorbidity challenged their clinical routines and challenged their ability to manage these patients effectively.

When talking about their interactions with patients with multimorbidity, three main issues emerged from the data:

1. Complexity – in terms of presentations, symptom management and patient characteristics;
2. Uncertainty – in terms of treatment and management;
3. Emotional strain – associated with managing complex patients who show little improvement or willingness to engage in their own care.

Complexity. Practitioners all stated that dealing with multiple conditions increased complexity. GPs highlighted that they often used clear and protocolised guidelines when dealing with single conditions, but lacked guidance and clear referral pathways when dealing with multiple conditions at once:

Yes. I think a single long-term condition is much, much easier to deal with. From the point of interactions and how they feel and perceive themselves. Definitely, thinking of patients who unfortunately have a heart problem, but the problem's been investigated at the hospital, dealt with, and there's a clear plan of action as opposed to adding another scenario to that definitely. (DR2, female (F), GP partner)

Multimorbidity introduces a level of complexity about patient presentations and symptoms, with practitioners finding it difficult to separate out conditions to determine which symptoms relate to which condition, and to recognise the development of new conditions:

And the challenge also is are those symptoms due to the medication or is there another physical symptom going on? Does she warrant another referral for investigation? (DR2, F, GP partner)

Some GPs described how multimorbidity also made it more difficult to process information and effectively monitor or predict potential problems:

... treating becomes more complex but then I also think explaining things, watching things and being aware of all the different possible things that could happen physically, becomes more difficult so the side effects from all the drugs, all the interactions they all become more difficult. (DR16, F, trainee GP)

Complexity also framed relationships with patients with fatalistic attitudes to health and disease, making it difficult for nurses to engage some multimorbidity patients with advice about their health. When asked about what factors might impact on treating patients with multiple conditions, one nurse stated,

You get a lot of patients who are in denial, don't want to know, aren't bothered and they'll turn around and say 'I don't care,

I've got this, I don't care I'm just going to live my life to the full'. (PN2, F, practice nurse)

Uncertainty. Multimorbidity was seen to be inextricably linked to treatment complexity, which was essentially characterised by uncertainty about treatment decisions. This led to some GPs describing clinical uncertainty in treating patients with multimorbidity. This characterisation was not limited to GP trainees but also applied to senior GPs with many years of experience:

Struggling yeah, it's just not feeling that confident, not feeling that confident about managing one condition, but realising it has an impact on the other one, affecting it adversely. I'm not sure what balance to strike. (DR12, male (M), GP partner, 20 years qualified)

Much of this uncertainty was a result of the difficulties in prescribing appropriately and using disease-specific guidelines that do not take into account interactions owing to multimorbidity. For example, practitioners found it difficult to ensure that patients were prescribed all recommended medications without risking adverse interactions. But quite apart from concerns about adverse drug interactions, practitioners also encountered problems when monitoring conditions that may be unrelated, or where management is antagonistic between conditions. When asked whether working with patients with multiple conditions as opposed to those with single conditions presented specific challenges, a nurse recounted that

... you might be thinking of giving them something but then you have to consider what other conditions they've got and the potential side effects and interactions and also whether what you're going to put them on, is it going to cause a problem with another existing condition. So, yeah, they're not straight forward. (PN1, F, practice nurse)

Some GPs emphasised that in the presence of such complexity and uncertainty, general practice became more reliant on a capacity to adapt existing evidence-based approaches to fit the heterogeneous needs of patients with multimorbidity:

If you've just got atrial fibrillation and you fit in with the NICE Guidance then you can apply the evidence can't you, its protocol driven medicine. So I think that's the difference, when you look at protocol driven medicine, [...] whereas really what you've got to try and do is use your acumen and your professional judgement to see to what extent you can apply these protocols to help people improve their health. (DR8, M, salaried GP)

Emotional strain. As a consequence of struggling with complexity and uncertainty, practitioners felt that treating patients with multiple and possibly competing health conditions threatened their resolve and resilience, leading to negativity that might spill over into the consultation:

Not worn down, that's not the right word, but they are difficult to manage because they don't seem to get any better and then obviously that has a psychological impact probably on the doctor and on the patient. (DR9, F, GP partner)

In describing the psychological impact incurred, practitioners also highlighted that consultations with patients with multimorbidity affected their motivation and reduced their capacity to cope with uncertainty and complexity. One GP who regularly saw a patient with diabetes, depression, arthritis and fibromyalgia confessed that his ability to help complex patients with multiple conditions was sometimes seriously impaired by low motivation and an absence of a management plan:

One is my own feelings because when that kind of person comes in my heart sinks a little because I'm thinking what do I do now? I'm thinking what am I going to do this time? Will I be able to cope? (DR1, M, GP partner, 30 years qualified)

Patient experiences of multimorbidity

When discussing patient experiences of multimorbidity, a number of themes emerged from the data. Impact on physical ability and emotional strain were key themes. In addition, the challenges of living with multimorbidity in terms of understanding interactions and relationships between conditions, complexity of treatment regimens and treatment burden were identified by many of the patients.

Multimorbidity was not a constant phenomenon across all patient narratives and only came into view for those patients where burden was heightened over and above that experienced in day-to-day life:

... so I guess I kind of manage it day by day and sometimes you don't realise how bad it is until you think, 'Hang on a minute, I can't do this, this and this'. (P3, F, 57 years, OA and CHD)

Many patients described the burden caused by the physical impact of their conditions, affecting their day-to-day and social lives:

We don't go out now, basically. I've been a Freemason for many years. Every Lodge Meeting has a dinner after. There are times when I can't stay for dinner. I'm so tired I have to go. That is a bit embarrassing (P11, M, 76 years, OA and CHD)

Burden associated with multimorbidity often led to reductions in mobility, loss of independence and feeling slowed down by their conditions:

Because there's loads of things that I could do and can't do now and I can't do it without anybody with me, I can't do anything if I'm on my own. (P1, F, 68 years, OA, CHD and Dep)

The progressive nature of multiple conditions could also lead to additional burden on patients:

... but because I've got all these things going round, what's happening is I'm just going down and down in a vicious circle getting physically ... I can see it, getting physically more feeble. (P17, F, 63 years, DM and Dep)

Physical limitations caused by their health conditions also had mental or emotional implications for patients, especially following a new diagnosis (e.g. diabetes) after coming to terms with living with other long-term conditions (e.g. arthritis):

So I think it wasn't until about, probably about four or five months later that it started to hit me, the implications of that, and I found that very hard to deal with and I tried not to think about it. (P12, F, 57 years, DM and OA)

To what extent the impact of multimorbidity registered with patients was in part related to the social and psychological consequences of multimorbidity. For example, an inability to conceal poor health in social environments often led to feelings of embarrassment and frustration, affecting patients' personal identity. Many patients also described the impact their health had on their mood, displaying signs of low mood and depression:

My wife had to do everything. She does everything, I can't do it. It's embarrassing. I can't lift anything. If we go anywhere and we've got a suitcase, my wife has to carry it. Well wheel it about and lift it. I can't do it. I just can't do it. It's embarrassing. I don't know I just get fed up sometimes. It's very depressing, very depressing. (P11, M, 76 years, OA and CHD)

The presence of multimorbidity also registered with patients when the treatment and care were particularly burdensome, for example, when they received repeated appointments with different health services,

You know, oh I can't go shopping today, I can't do this today because I've got to go to the nurse and you know it takes over your life really. (P1, F, 68 years, OA, CHD and Dep)

or when they were prescribed complicated medication regimens,

Codeine can make me constipated and then I take stuff for constipation and that can give me tummy ache. And then you think, 'Oh this is just horrible!' But you know that you have... you know, you can't just stop it altogether so you have to then take something to then counterbalance something else. (P3, F, 57 years, OA and CHD)

and also when they felt overwhelmed by the self-management advice given,

I was getting myself all you know, anxious coming in, you know, I mean I didn't fall out with my doctor but I told him I

couldn't do this physio thing because of the arthritis. (P10, M, 68 years, OA, CHD and Dep)

However, some patients reported very little impact from having multiple as opposed to single conditions, and not all patients felt that having multiple conditions led to additional burden associated with managing their health. These patients often described how they followed the advice they were given and took the medications they were told to take, requiring little further support from their primary care providers:

Well I actually don't find it a huge problem. I'm one of these people that thinks whatever you get in life you just get on and deal with it. And it doesn't restrict me in any way really. (P8, M, 67 years, DM and CHD)

Most of these patients appeared to take a pragmatic view of life:

I tend not to think about it, you know. It's just one of these things. I've always been the same, I just get on with life. You've just got to deal with it. (P4, M, 58 years, CHD and Dep)

Of the 20 patients, 6 fell into this broad category (P2, P4, P8, P10, P15 and P18). There was no obvious pattern in terms of combinations or numbers of conditions (3 had 3 conditions and 3 had 2 conditions), presence of depression (4 had depression 2 did not) or levels of deprivation (3 were living in a deprived area and 3 were not; see Table 1) which characterised these patients.

The role and concepts of self-management

As well as exploring what multimorbidity meant to practitioners and patients, we also looked at how attitudes to self-management related to these concepts of multimorbidity. Here, we were interested to learn whether experiences of multimorbidity among practitioners and patients impacted on attitudes to and experiences of self-management. When discussing the concept of multimorbidity, the issue of self-management was seen as a key factor for all of the practitioners who were interviewed.

For healthcare practitioners, self-management was viewed as comprising many different health behaviours summarised into three themes: appropriate help-seeking, compliance with medication and healthy lifestyle choices. Practitioners described good self-managers as patients who presented to healthcare services at appropriate times and knew when to seek help, for example, at the time of an exacerbation. Patients were often perceived to be poor at differentiating when to and when not to seek help, leading to either an over-reliance on medical care, or presenting too late to receive appropriate treatment and prevent complications. Practitioners' interests in promoting self-management in

multimorbidity stemmed primarily from a need to reduce service use:

Sometimes they'll not always need to come, like, if they've got a cold and need to maybe up their inhalers slightly until they get over a cold, its not always necessary but identifying at what point is suitable to come in and hopefully, you know, lessen their appointments that they need by looking after themselves. (PN2, F, practice nurse)

In contrast, patients' motivations to self-manage were not premised on a desire to reduce their use of healthcare. Indeed, many patients viewed seeing their GP or nurse as a 'last resort' and did not believe that they visited their GP as often as they would have perhaps preferred to. Often, their reluctance to visit their practice owed to their desire to see the same doctor as they valued the continuity of care:

... but I thought it's a waste of time making appointments, you're just wasting time somebody else could use. So unless it's something absolutely life threatening [I don't make an appointment]. (P16, F, 58 years, Asthma and DM)

... if you want to see a particular GP, sometimes, an appointment can be a month ahead and if you're worried about your palpitations in the middle of the night, that's not much of a help really, you know, so that's quite difficult. (P5, F, 58 years, DM and CHD)

Many patients commented that they actually felt they had had little contact with healthcare services:

... unless something flares up like it did last week on Tuesday, I don't like going when I don't need to go. (P4, M, 58 years, CHD and Dep)

Instead, patients tended to be motivated to self-manage to help reduce the impact of their conditions on their daily routine and lifestyle. When describing how they looked after themselves, patients often described instrumental activities aimed at improving their lives and their independence:

And I've built in a downstairs toilet which has made my life so much easier, and ... but self-care, yes, I've got showers. [...] So I don't actually need any assistance as such I've got rails up the stairs. So anything that I can do to make my life easier I've already put into place. (P3, F, 57 years, OA and CHD)

Discussion

Summary of main findings

Patient and practitioner concepts and understanding were driven by the impact of multimorbidity. Practitioners characterised multimorbidity in terms of complexity and uncertainty, which sometimes caused them emotional distress. The difficulties experienced by healthcare practitioners were

universally recognised across the sample, with no difference by area (levels of deprivation), gender, years of experience or by role (GP/nurse). Patient experience was more varied depending on burden, disablement and emotional impact. Perceptions of increased treatment burden and increased disability led to patients reporting greater emotional distress. A key finding was that some patients did not perceive multimorbidity as problematic. The reasons for this are unclear, but this group should be recognised as a distinct subgroup, worthy of further research, rather than as deviant cases.

Self-management was seen by practitioners to be a key element of managing multiple conditions. However, there were differences in the practitioner and patient drivers for self-management and in their definitions of success. For practitioners, the aim of patient self-management was to reduce patients' needs for healthcare appointments and use of unscheduled care. In contrast, patients felt that the value of self-management lay in enhancing their lifestyle and improving functioning and quality of life, and this has implications for measuring benefit of interventions designed to manage multimorbidity.

Strengths and limitations

A key strength of this research was the inclusion of both patients and practitioners to explore their views about the meaning of multimorbidity, its implications for key stakeholders and the role and purpose of self-management in multimorbidity, as previous qualitative studies have tended to focus only on one of these groups.^{10,16} Selecting the interview sample from patients who completed the survey phase of the study allowed us to purposively sample patients based on a range of demographic and medical variables, ensuring a diverse sample. There was a relatively low response from patients from ethnic minorities to the survey (1.6%; $n = 7$), and previous research has shown high rates of multimorbidity in minority populations, which are currently underserved by the health system.¹⁷ Therefore, further research is needed to explore potential differences in the conceptualisation of multimorbidity and self-management within different minority groups. The majority of practitioners were also purposively sampled, but snowball techniques were also necessary because this study was not able to financially compensate practitioners for their time, which in some practices led to poor uptake. Sampling was limited by practitioner agreement and availability for interview.

Comparison with other studies

Increased burden and emotional strain were experienced by practitioners particularly when faced with patients who showed continued lack of improvement. This may suggest that these attitudes do not relate to multimorbidity per se, but to working with complex patients who fail to improve. GPs talked about how they had to overcome their own negative

attitudes in relation to these patients who they described as 'heart-sink patients'. As in the research of O'Brien et al.,⁷ in which practitioners described working with patients with multimorbidity as 'exhausting', 'demoralising', 'overwhelming' and 'soul destroying', practitioners in this study used similar emotive words when talking about patients with multimorbid long-term conditions. O'Brien et al.⁷ concluded that the negative responses practitioners felt in response to multimorbidity were at least in part due to the pressures of working with socially deprived populations. However, we found that practitioners from practices from a range of affluent and deprived populations held equally negative views about multimorbidity, suggesting that negative attitudes in this context are more a response to dealing with complex patients than working with patients from poor socioeconomic backgrounds.

Patients often only recognised multimorbidity when their coping mechanisms were exhausted and their illnesses became burdensome, or when their identity was threatened. This ties in with the work of Charmaz,¹⁸ who described how long-term conditions that cause impairment intrude on a person's daily life and undermine their perceptions of self, resulting in an enforced change in identity. However, not all patients experienced multimorbidity in this way. It is not clear why some patients were less troubled than others, but it may be that they were less ill, or that they were much more adept at undertaking key tasks assigned to sick roles, such as adhering to the advice of health professionals and taking medicines as prescribed. They may also have been more resilient than other patients, leading to a more pragmatic and flexible attitude about managing health. As in the research of Morris et al.,¹⁹ which reported that burden was not inevitably increased in all patients with multimorbidity, perceived levels of burden were subject to fluctuation and change over time. As the interviews in this study were completed at only one time point, it may be that patients' views of whether multimorbidity increased burden may also change depending on how 'well' they felt at the time of interview. The differentiated response among patients to multimorbidity may also owe to the fact that some were more resilient than others. Resilience in the face of chronic physical illness is known to be a psychological trait associated with better mental health and enhanced capacity to cope with and self-manage illness,²⁰ but the extent to which this applies to multimorbidity is unknown and warrants further research.

Implications for research and practice

Self-management is seen as an important part of managing long-term conditions particularly in multimorbidity. As perhaps may be anticipated, problems about how to support self-management are magnified in people with multimorbidity. Self-management was recognised as important by both practitioners and patients. However, practitioners in this study felt that patients struggled to self-manage. This

perception may have been reinforced by the burden and emotional strain practitioners faced when dealing with patients who failed to achieve good self-management. Alternatively, the burden and strain experienced by practitioners may owe to their own struggles to motivate patients to self-manage in the absence of guidance and support to help them achieve this aim. Barriers to self-management may therefore be present where practitioners and patients hold different motivations to promote and engage with self-management and define successful self-management differently. Practitioners typically signed up to service-led incentives to promote self-management which centre on initiatives to reduce demand for services, whereas patients were more motivated to self-manage for personal reward.

The use of existing condition-specific guidelines in the presence of multimorbidity is only likely to exacerbate complexity and uncertainty, rather than help solve problems.¹² Improved integration of clinical guidelines, which currently follow single-condition models,^{9,21} may help reduce the clinical uncertainty that practitioners face when dealing with patients with multiple conditions. However, before reconfiguring services of NHS, as suggested by many experts in the field,^{1,8,9} we need to take into consideration what multimorbidity means to different stakeholders. It has been recognised and our study would support that care for multimorbid patients should in part be driven by individual patient preferences and priorities, including a recognition of when to stop giving care.²² Additionally, better healthcare for patients with multimorbidity may need to balance patient priorities with a need to allow clinicians freedom and confidence to make judgments in the face of complexity and uncertainty.²³

Research shows evidence of high levels of primary and emergency unscheduled care use in this population,^{4,24} but there has been little exploration of whether these patients feel that they do overuse services or what they would hope to achieve in successfully self-managing their conditions. One key difference in practitioner and patient views of self-management was that patients felt that they did not access healthcare unnecessarily and that their aim would not be to reduce the contact they have. The aim of the current NHS strategy for treating patients with long-term conditions is to improve self-management and therefore reduce patients' need for healthcare appointments and unscheduled care. However, if patients do not think that they are using healthcare, excessively improving self-management may not result in reduced service use, which may in part explain the largely negative results of self-management interventions in people with long-term conditions.²⁵

Conclusion

There have been recent calls to improve existing guidelines to facilitate more effective management of multimorbidity. Indeed, in the English NHS, the National Institute for Health and Care Excellence is currently deciding on the scope of a

multimorbidity guideline. However, this study suggests that guideline development of this kind should take into account the gap in perceptions among practitioner and patients about experiences of multimorbidity. Not least, guidelines would need to acknowledge the tension between practitioners' and patients' accounts about self-management in the presence of multimorbidity. Interventions that can enhance both practitioners' and patients' experience of living with multimorbidity and facilitate self-management are few, and there is scope to develop cost-effective interventions that can improve health outcomes among growing numbers of people with multimorbidity.

Acknowledgements

We would like to thank NIHR Primary Care Research Network – Northwest for its support in recruiting GP practices and in providing support with patient identification through quality and outcomes framework (QOF) registers. We would also like to acknowledge the practitioners and patients who took part in the interviews and also the support staff at the participating sites.

Declaration of conflicting interests

This article presents independent research commissioned by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors and not necessarily those of the National Health Service (NHS), the NIHR, or the Department of Health. The funders had no role in the design and conduct of the study; the collection, management, analysis and interpretation of the data; and the preparation, review or approval of the article. None of the authors have conflicts of interests to declare.

Funding

This research was funded by the National Institute for Health Research (NIHR) School for Primary Care Research and a Research Capability Funding grant from the NIHR Collaboration for Leadership in Applied Health Research and Care for Greater Manchester.

References

1. Barnett K, Mercer SW, Norbury M, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012; 380: 37–43.
2. Van Weel C. Chronic diseases in general practice: the longitudinal dimension. *Eur J Gen Pract* 1996; 2: 17–21.
3. Anderson GF. *Partnership for solutions. Better lives for people with chronic conditions*. Baltimore: Robert Wood Johnson Foundation and Johns Hopkins University, 2002.
4. Salisbury C, Johnson L, Purdy S, et al. Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. *Br J Gen Pract* 2011; 61(582): e12–e21.
5. OECD health reform: meeting the challenge of ageing and multiple morbidities. OECD Publishing, <http://dx.doi.org/10.1787/9789264122314-en> (2011, accessed 2 November 2012).
6. Valderas JM, Starfield B, Sibbald B, et al. Defining comorbidity: implications for understanding health and health services. *Ann Fam Med* 2009; 7: 357–363.

7. O'Brien R, Wyke S, Guthrie B, et al. An 'endless struggle': a qualitative study of practitioners' and practice nurses' experiences of managing multimorbidity in socio-economically deprived areas of Scotland. *Chronic Illn* 2011; 7: 45–59.
8. Bower P, Harkness E, Macdonald W, et al. Illness representations in patients with multimorbid long-term conditions: qualitative study. *Psychol Health* 2012; 27(10): 1–16.
9. Salisbury C. Multimorbidity: redesigning health care for people who use it. *Lancet* 2012; 380: 7–9.
10. Bower P, Macdonald W, Harkness E, et al. Multimorbidity, service organization and clinical decision making in primary care: a qualitative study. *Fam Pract* 2011; 28: 579–587.
11. Parekh AK and Barton MB. The challenge of multiple comorbidity for the US health care system. *JAMA* 2010; 303: 1303–1304.
12. Van Weel C and Schellevis FG. Comorbidity and guidelines: conflicting interests. *Lancet* 2006; 367: 550–551.
13. Strauss A and Corbin J. *Basics of qualitative research techniques and procedures for developing grounded theory*. 2nd ed. Thousand Oaks, CA: SAGE, 1998.
14. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3(2): 77–101.
15. Henwood KL and Pidgeon NF. Qualitative research and psychological theorizing. *Br J Psychol* 1992; 83(1): 97–111.
16. Bayliss EA, Steiner JF, Fernald DH, et al. Descriptions of barriers to self-care by persons with comorbid chronic diseases. *Ann Fam Med* 2008; 1: 15–21.
17. Mathur R, Hull SA, Badrick E, et al. Cardiovascular multimorbidity: the effect of ethnicity on prevalence and risk factor management. *Br J Gen Pract* 2011; 61(586): e262–e270.
18. Charmaz K. The body, identity and self: adapting to impairment. *Sociol Quart* 1995; 36: 657–680.
19. Morris RL, Sanders C, Kennedy AP, et al. Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. *Chronic Illn* 2011; 7: 147–161.
20. Stewart DE and Yuen T. A systematic review of resilience in the physically ill. *Psychosomatics* 2011; 52(3): 199–209.
21. Guthrie B, Payne K, Alderson P, et al. Adapting clinical guidelines to take account of multimorbidity. *BMJ* 2012; 345: e6341.
22. Mangin D, Heath I and Jamouille M. Beyond diagnosis: rising to the multimorbidity challenge. *BMJ* 2012; 344: e3526.
23. Roland M and Paddison C. Better management of patients with multimorbidity. *BMJ* 2013; 346: f2510.
24. Dickens C, Katon W, Blakemore A, et al. Does depression predict the use of urgent and unscheduled care by people with long term conditions? A systematic review with meta-analysis. *J Psychosom Res* 2012; 73: 334–342.
25. Foster G, Taylor SJC, Eldridge SE, et al. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database Syst Rev* 2007; 4: CD005108.

Appendix I

Patient interview schedule

Introduction. Relevant Information concerning clinical characteristics such as diagnosed conditions, presence/absence of depressed mood collected from the survey, will be confirmed with the patient to introduce the topic:

- According to the information you gave us on the questionnaire you completed, you have ... (*list which out of 5 conditions they have to focus them on these*)
- I'd like you to tell me a bit about what it is like to live with those conditions.

Understanding and defining self-care. How does the patient define self-care, what is their understanding, how do they apply it

- What do you think when we talk about self-care? How would you define it?
- How do you try to look after yourself?
- Do you ever experience difficulties in managing your different conditions?

Experiences of self-care and how it has evolved. Level of self-care, reliance on carers/professionals, confidence in

maintaining self-care, social/emotional support and professional–patient relationship/patient-centredness:

- Who would you say takes the most active role in care for your conditions? In what way?
- What role do carers/healthcare professionals take in your care? How has this changed over time? Do you feel this has been adequate/enough?
- What role do you take in the management of your own conditions?
- Whose responsibility do you think it is to manage long-term conditions?
- Do you think you could do anything more than you do already? If so, what stops you?
- Do you think you manage all of your conditions equally well? Do you have support for all of them or for some but not others?
- How confident are you in maintaining your own conditions? Is there anything you have difficulty with? What do you do if you are unsure of any aspect for managing your conditions?
- Do you feel you have enough social/emotional support for managing your conditions? Where do you get this support from? Ideally, where would you get it from?
- Does your doctor/nurse discuss self-management of your conditions with you? How much does your doctor/nurse include you in decisions about your care?

Contact with health services/self-care support.

- What do you think when we talk about *supported* self-care? How would you define it?
- Do you know about local self-care support groups in your area? Or other resources such as online support groups? Depending on answer:

YES – which ones, how referred (self/general practitioner (GP)/other), feelings about it and how long attended:

- How did you find out about them?
- Have you been involved with any self-care support such as the Expert Patients Programme (EPP), disease-specific programmes (e.g. diabetes/CHD), community support groups, online communities and so on? Which ones have you tried?
- How do you access these groups (attend meetings/phone lines/online)?
- Are they general or disease specific? How do they deal with the management of multiple conditions?
- Are you still attending? How long did you attend/how long have you attended?
- How do you feel about these groups? (have they helped/in what way/would you recommend to others?) Do you think they helped you to deal with managing multiple conditions?
- Is there anything you now do differently as a result of having attended? Have they helped you balance the management of all your conditions together?
- Have they met your expectations?
- Did you have any difficulties in finding out about/attending any of these groups? How did you overcome these difficulties?

NO – knowledge about resources, any referral by practice (GP/nurse), why not tried = barriers (social, health and logistics), feeling ‘ready’ and expectations:

- Have you ever discussed self-care support groups such as the EPP, disease-specific programmes (e.g. diabetes/CHD), community support groups, online communities and so on with your doctor/nurse?
- Have you ever thought of accessing any of these?
- If YES – do you think you will try any of these? Which ones interest you? What are your expectations of these groups/what do you expect to get from them?
- If NO – why do you think you won’t try them? What do you think is stopping you from trying them? What are your expectations of such groups? Do you think you are ready to take part in such programmes?

Barriers to supported self-care/programmes. Disablement, financial constraints/costs, low level health literacy, logistical

problems, persistent depressive symptoms and balance between illness and quality of life

- What do you think stops you from getting involved in supported self-care programmes?
- Do you find it hard to access healthcare? What if anything do you think would help access?
- Do you think the programmes available are suitable for you? (multimorbid conditions/ethnicity/similar life experiences/age/gender etc.)?

Appendix 2*Practitioner interview schedule*

Introduction. The practice – list size, number of practitioners (roles/grades), levels of long-term care (LTC)/multimorbid LTC, patient demographics/level of social deprivation and how currently manage these patients.

Understanding and defining multimorbidity

Multimorbidity outcome for patient health, diagnosis, role of depression/low mood, prioritising conditions and understanding of antagonism between conditions:

- How would you define multimorbidity?
- Could you give some examples of patients with multimorbidity?
- Do you think there are any specific challenges in managing these patients?
- What proportion of these patients struggle to cope with their conditions? Why don’t they cope well?

Understanding and defining self-care/supported self-care. How do they define self-care/supported self-care, how do these differ, what is their understanding of these terms and how do they apply them in practice:

- How would you describe patient self-care?
- What do you think the role of patients is in self-care? What does it entail?
- What is your understanding of supported self-care?
- How do you apply these in your practice
- How do you describe these to patients?

Experiences of promoting self-care and how it has evolved. Promotion of self-care, active promotion, use of care plans, responses from patients and confidence and ability in this process:

- How do you feel about the idea of patient self-care?
- What would you say your approach to self-care/supported self-care is like? (active, not a priority)

- How do patients generally receive advice about self-care?
- What do you think are the main barriers to patients engaging in self-care? What effect do you think multimorbidity has on barriers?

Promotion of supported self-care, awareness of chronic disease self-management programme (CDSMP), for example, EPP, active promotion, worth of such programmes and patients' responses to suggestions (positive/negative and resistance)

- What do you know about local self-care support programmes?
- How do you bring these to the awareness of patients?
- How well are these recommendations usually received? Any resistance? Any differences between patients with single or multiple conditions?
- What proportion of your patients do you think attend such programmes? Again, any differences between patients with single or multiple conditions?
- How do you value such programmes for patients?
- Do you think patients have the competency for self-care? Do you think multimorbidity affects ability to self-care? In what way?
- Do you think the programmes available meet the needs of your patients? Would you like any different/additional programmes available?
- If you could design a supported self-care programme for your patients, what would it look like?
- Do you think the programmes out there are suitable for multiple conditions? Do you feel they deal with the complexity of managing multiple conditions?

Barriers to supported self-care programmes

Patients who do not access services. Perceived/reported barriers (disablement, financial constraints, low level health literacy, logistical problems, persistent depressive symptoms and balance between illness and quality of life) and suitability of specific programmes for multimorbid conditions

- Do you follow up suggestions to patients about attending supported self-care groups?
- For those patients who do not attend any, do you inquire why?
- What reasons have patients given you for not attending programmes? (explore barriers)
- Do you give patients advice about overcoming barriers?
- What do you perceive as the impact of persistent depressive symptoms on attending programmes?

Patients who do access services. Motivations, benefit to patient/practice, impact on management of conditions/health/quality of life and initial barriers

- How were barriers overcome?
- How motivated do you find patients when they discuss supported self-care programmes?
- If initial barriers were discussed, how were these overcome?
- What benefits do you think these programmes bring to the patient?
- What do you think is the impact on patient management of conditions/overall health/quality of life?
- What benefits do you think these programmes bring to the practice? (any reduction in service use)