

# BMJ Open Capturing the experiences of patients across multiple complex interventions: a meta-qualitative approach

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## ABSTRACT

**Objectives:** The perspectives, needs and preferences of individuals with complex health and social needs can be overlooked in the design of healthcare interventions. This study was designed to provide new insights on patient perspectives drawing from the qualitative evaluation of 5 complex healthcare interventions.

**Setting:** Patients and their caregivers were recruited from 5 interventions based in primary, hospital and community care in Ontario, Canada.

**Participants:** We included 62 interviews from 44 patients and 18 non-clinical caregivers.

**Intervention:** Our team analysed the transcripts from 5 distinct projects. This approach to qualitative meta-evaluation identifies common issues described by a diverse group of patients, therefore providing potential insights into systems issues.

**Outcome measures:** This study is a secondary analysis of qualitative data; therefore, no outcome measures were identified.

**Results:** We identified 5 broad themes that capture the patients' experience and highlight issues that might not be adequately addressed in complex interventions. In our study, we found that: (1) the emergency department is the unavoidable point of care; (2) patients and caregivers are part of complex and variable family systems; (3) non-medical issues mediate patients' experiences of health and healthcare delivery; (4) the unanticipated consequences of complex healthcare interventions are often the most valuable; and (5) patient experiences are shaped by the healthcare discourses on medically complex patients.

**Conclusions:** Our findings suggest that key assumptions about patients that inform intervention design need to be made explicit in order to build capacity to better understand and support patients with multiple chronic diseases. Across many health systems internationally, multiple models are being implemented simultaneously that may have shared features and target similar patients, and a qualitative meta-evaluation approach, thus offers an opportunity for cumulative learning at a system level in addition to informing intervention design and modification.

## Strengths and limitations of this study

- A total of 62 interviews were included in this analysis incorporating experiences from 44 patients and 18 caregivers.
- The primary intention of the original qualitative design was to capture evaluation information across all projects in a systematic and standardised way. However, this was not always possible given the range and complexity of interventions that resulted in variability of approaches in data collection.
- A qualitative meta-evaluation approach offers an opportunity for cumulative learning at a system level in addition to informing intervention design and modification.

## BACKGROUND

Improving care for individuals with complex health and social needs has been increasingly identified as a critical focus in order to maintain and improve equitable access to quality care and decrease system inefficiencies.<sup>1</sup> Patients with complex health and social needs, defined as having two or more co-existing chronic conditions,<sup>2</sup> are frequently identified as high utilisers of emergency and inpatient health services.<sup>3</sup> This patient group is often described as most likely to benefit from care coordination efforts and as contributing significantly to healthcare system costs.<sup>1-9</sup> Individuals with multiple comorbidities, who frequently experience mental health problems and illnesses,<sup>4</sup> are often of low socioeconomic status<sup>5</sup> and have unmet basic needs, such as housing, employment and transportation.<sup>7 8 10</sup>

The care and management of individuals with multiple chronic diseases may involve complex interventions comprised of behavioural, organisational and technological components that may act both independently and



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interdependently.<sup>11 12</sup> However, the significance of patients' social locations and how they interact with health and social services is often missing in the design of complex interventions.<sup>7 13</sup> Protocols for the implementation and evaluation of complex interventions for patients with multiple chronic diseases often assume a single, universal patient trajectory or journey.<sup>14</sup> As a result, interventions targeting this patient group often include self-management strategies that do not consider the patient's physical, social and economic challenges.<sup>7 15–17</sup> In addition, patient preferences and perceptions of innovative care models may be overlooked in their design and implementation.<sup>18 19</sup> This is not to say that providers are unaware of their patient's complex life contexts or lack empathy. However, despite many recent initiatives internationally to address this gap, there remains a lack of clarity as to how individual healthcare providers or projects could best address systemic issues outside of their control that might better allow for the delivery of patient-centred care.<sup>18</sup> While intervention outcome measures such as reduced emergency department (ED) visits reflect system priorities, these metrics may not address what matters most to the patient.<sup>20</sup> As well, the interaction of multiple level system components is often inadequately theorised.<sup>21–24</sup> As a result, intervention components typically focus on the individual level (patient or caregiver), local context (clinic or hospital) or system level (economic or policy); even though these are inter-related components within complex systems.<sup>23 24</sup>

Researchers have explored the health and social care experiences of patients with multimorbidity,<sup>15 25 26</sup> including patient perceptions of intervention components<sup>17</sup> and barriers to the translation and implementation of patient-centred strategies into primary care settings.<sup>27–30</sup> Our study contributes to critical studies of care for patients with multiple chronic conditions by highlighting and challenging some of the key assumptions embedded in the design of complex interventions. We examine these underlying logics by drawing on the experiences of patients with multiple chronic diseases from the qualitative study component of five complex intervention projects that were implemented in Toronto, Ontario, Canada. BRIDGES (Building Bridges to Integrate Care) was initiated in 2011 at the University of Toronto to improve care coordination for patients with complex medical and social needs. To date, nine project teams targeting patients with various conditions have received methodological and financial support for the design and evaluation of these innovative interventions. This pragmatic qualitative meta-evaluation provides a unique opportunity to compare findings across multiple innovative interventions that seek to address similar care issues through a variety of approaches and with different patient populations.

## METHODS

We undertook a cross-study evaluation of five projects that each addressed the needs of a specific patient

population through different complex interventions (see [table 1](#) below for a description of each of the five projects). This study was conducted in addition to the individual qualitative and quantitative evaluation undertaken by each team. The projects were designed to integrate services by medical providers from community, primary and hospital care settings. While these interventions were distinct, they all focused on developing innovative models of health service delivery to reduce avoidable hospitalisations, readmissions and ED visits through better integration of care. These models targeted patients who are most likely to use inpatient and ED services, such as those with multiple chronic diseases.

A qualitative descriptive design<sup>31</sup> was adapted for the original project-level evaluations for several reasons, including the attempt to standardise data collection and analysis across several projects as much as possible and to improve the feasibility of the study design. We drew on realist evaluation in our design as it is a theory-driven model that is designed to explicate how and why a particular intervention or programme of interventions succeeds or fails.<sup>32</sup>

Three different sets of standardised semistructured interview guides were developed to collect data from patients, informal caregivers and medical providers (see online supplementary appendix A). These interviews were not analysed as dyads but rather were treated as separate data. The guides were adapted by each project team to conduct an outcome evaluation specific to their intervention. This enabled individual study teams to evaluate outcomes of their specific interventions while simultaneously exploring themes common to all projects. In accordance with qualitative research, the sampling design was purposive rather than experimental and depended on the stage that each team had reached in terms of their own data collection at the time of this analysis.<sup>33</sup> We chose not to continue our transcript review as more data became available as we felt we had reached saturation on the themes we had identified. It is worth noting that our approach was not a synthesis, that is, we did not conduct a meta-ethnography of the findings from unrelated qualitative studies across a common theme. Rather, our pragmatic approach to qualitative meta-evaluation allowed us to retain the flexibility and local focus of most qualitative studies standardised across multiple projects. Combining both breadth and depth in this manner, in a prospective design, allowed for both individual project evaluation and insight into broader systems issues being experienced across disease groups.

Interview guides were organised around the time points of 'before, during and after' the intervention in order to explore experiences of care and potential changes in patient experience across these time frames. This allowed for individual teams to perform a basic before and after analysis of their interventions but was not included in our analysis of broader themes. The questions and prompts were exploratory in design

**Table 1** BRIDGES projects

Intervention	Project	Description	Patient interviews	Caregiver interviews
1	IHBPC	Designed to integrate care by providing home-based primary care to homebound patients through a Community Support Agency (House Calls model) or a FHT	12	14
2	IMPACT+	Designed to integrate care by simultaneously bringing patients, families/caregivers, the primary care team, community care providers and hospital-based specialists together in real time and space to assess the medical, functional and psychosocial needs of the patient	3	1
3	Afib	Designed to integrate care by redesigning and optimising processes of care for patients with AF in the ED and the way in which follow-up care is provided as they transition from the ED to primary care	7	NA
4	PIC-COPD and other comorbidities ()	Designed to integrate care by engaging in care coordination and management activities that includes case management, individualised action plans and COPD patient education	11	3
5	CATCH-ED	Designed to integrate care for individuals with mental health and addictions disorders by identifying these patients and connecting them to primary care and a range of community support options from which creative, individualised and integrated responses can be developed	11	NA
Total			44	18
				62

AF, atrial fibrillation; Afib, Innovate Atrial Fibrillation; CATCH-ED, Coordinated Access to Care from Hospital Emergency Departments; ED, emergency department; FHT, Family Health Team; IHBPC, Integrated Home-Based Primary Care; NA, not available; PIC-COPD, Program of Integrated Care for Patients with Chronic Obstructive Pulmonary Disease.

allowing for differences in participants' perceptions and experiences to emerge during the interviews.

To ensure some degree of standardisation in data collection across sites, a sociologist and member of the BRIDGES' Executive Committee (FW) led five workshops on qualitative methods for research teams from each of the five projects conducting the interviews. Research teams also had ongoing access to this individual as well as a Masters trained sociologist (JC) employed by BRIDGES to address methodological challenges. The patient interviews were conducted in person or by telephone depending on participant preference and each lasted approximately 30–45 min within a 1 year period. Interviews were audio-recorded and transcribed verbatim. All transcripts were initially reviewed by FW and JC who then conducted the preliminary analysis of common themes across the projects.

Following a thematic analysis approach,<sup>34</sup> FW and JC independently reviewed a series of purposively chosen transcripts from each of the projects and met twice to develop a coding framework as well as to enhance reflexivity through comparison of their individual assumptions about the data.<sup>31</sup> Transcripts were chosen using maximum variation sampling by asking the project teams to identify information-rich data across a wide range of differences such as age and gender (see online supplementary appendix B).<sup>35</sup> The framework consisted

of topics that were selected as being relevant across all projects and stakeholder groups. JC then coded the remaining interviews using NVivoV.10 software. The researchers' views and comments were recorded as marginal notes during the coding/theme development phase with the goal of focusing reflections around the emerging concepts. The researchers analysed and interpreted the data to identify similarities and differences across the interviews. These findings were then presented to multiple audiences including the BRIDGES Executive Committee that comprises a geriatrician, psychiatrist and family physician. A summary of the findings was also presented at a BRIDGES conference whose audience included clinical care providers, investigators and research assistants from all of the project teams and system stakeholders. These presentations served as a form of member checking to ensure the themes resonated with the project leads and care providers from the various sites. In addition, the manuscript was shared with the teams who contributed the original data for further review and comment.

## RESULTS

A total of 62 interviews were included in this analysis incorporating experiences from 44 patients and 18 caregivers (see online supplementary appendix C for

supplementary quotes). We identified five key themes shared across the different projects that captured patients' experiences and highlighted everyday assumptions about the patient standpoint that might not be addressed in the development of interventions designed to improve care for complex patients. In our study, we found that: (1) ED is the unavoidable point of care; (2) patients and caregivers are part of complex and variable family systems; (3) non-medical issues mediate patients' experiences of health and healthcare delivery; (4) the unanticipated consequences of complex healthcare interventions are often the most valuable; and (5) patient experiences are shaped by the healthcare discourses regarding medically complex patients.

### ED is the unavoidable point of care

Participants often reported that they did not want to go to the ED but believed that they had nowhere else to go. They often did not have a positive experience of the care they received in EDs, and one family caregiver described dissatisfaction:

The hospitals are ridiculous...You'd think, going to a hospital, that it's someplace where they're gonna take care of you, that they have facilities to be able to manage people who are sick and can't do things for themselves, and it's just not. (Caregiver, Intervention 1)

Patients reported at times what they assumed were judgements made by clinicians for accessing ED services. In the following account, a participant described his perception that a physician challenged him on being 'sick enough' and not wanting to (mis)use the ED:

I came to Emerg here and the doctor said to me—which I thought was very odd—"Why did you come today as opposed to yesterday or waiting 'til tomorrow?" I find that an odd question because, like, "Why do you think I'm here?...Its like, "Why, you think I'm not sick enough? I can't breathe, I feel like I can't breathe so I came here for help". (Patient, Intervention 4)

### Patients and caregivers are part of complex and variable family systems

Both patients and their informal caregivers described being part of complex family systems that varied and affected their capacity to meet often time-consuming and stressful care needs. One caregiver described their care responsibilities and the challenging and complex division of labour among family members:

When you're bombarded with doing everything like feeding, washing, cleaning, supervising, picking up materials and everything, it causes a lot of stress and conflict between family members and siblings who are supposed to be divvying up the responsibility...I mean the caregiving is done resentfully. (Caregiver, Intervention 1)

In addition to family members, some patients relied on close friends for caregiving support. But while these

participants appreciated the support of family and friends, others were unable to access a strong support system. The availability of caregiving support was shaped by a variety of factors such as geographical distance, work flexibility and intensity of care demands. Importantly, patients did not always desire family support. As one participant described:

For a good like two solid months I didn't have any contact with my parents, nor did I want to see them, just because it really affected my mental health. (Patient, Intervention 5)

Coordinating care was portrayed as a process of 'navigation' in a complex system. Caregivers described this coordination work as time consuming, isolating and ongoing. Caregivers often had to coordinate care that typically involved multiple tasks with several healthcare professionals, such as arranging transportation and scheduling appointments. One caregiver described these demands in addition to daily care activities that she was required to complete:

My dad had a lymphedema, due to cancer removal—a lymphedema in the arm—so he had one of those really tight elastic sleeves that had to be put on every day, so we had to do that every morning—and lots of doctors' appointments. There was the cancer doctor, and the family doctor, and the skin doctor and (laughs) the respiratory doctor 'cause he had respiratory problems, so lots of doctors' appointments. (Caregiver, Intervention 1)

While families played a central role in patient care, some caregivers reported their own needs were often unacknowledged. A caregiver reported the lack of available support services following her mother's death:

The social worker came...Within thirty seconds of her walking in the door I spent the next hour crying and talking non-stop so it was actually very helpful...She was to come back that Wednesday but my mom passed away on Tuesday. So I phoned the office to say "I'm really sorry I can't make the appointment." And the [community health agency] central office phoned me back to say "Well, now your services are terminated". Because they were attached to my mom, they weren't for me, they were attached to my mom and "Now she's dead, so I'm sorry we have to cut you off". (Caregiver, Intervention 1)

### Non-medical issues mediate patients' experiences of health and healthcare delivery

Non-medical issues such as financial stressors, social isolation, job insecurity, age and living arrangements were factors consistently described by patients as shaping their experiences of health and healthcare delivery. Inadequacy of social support, including housing, was a major issue described by many participants.

A patient participant described how the challenges of living on a limited income affected his health condition and specifically his ability to adhere to a healthy diet:



Right now the only problem we have is the Canada Pension and the old age, you know? I was getting more, like I said, I was getting more on disability, I was getting an allowance for food that I could eat because I was on a special diet—no sodium. (Patient, Intervention 4)

Other participants described the difficulty of adhering to medical treatment because they lived on a fixed income and had to direct their limited financial resources towards other essentials, such as rent and food. In the following quote, a family caregiver describes her efforts to keep ‘enough food in the house’ to enable healthy eating for her partner who suffers from multiple comorbidities including chronic obstructive pulmonary disease (COPD).

...I get paid on a Thursday and by the time all the bills are done I'm broke by Friday, right?...I said, "we're just still living paycheque to paycheque." There's times that we have no money at all, that I'm saying, "Oh, three days 'til payday. Three days!" But I try to make sure that there's enough food in the house for the two weeks, and there's enough, you know, his little vegetable treats that he likes, and I try not to let him eat too much junk food, but he likes his candies. (Caregiver, Intervention 4)

Financial instability often impacted patients' and caregivers' ability to access and maintain housing, and this impacted the care they were able to provide. Caregivers also described being mutually dependent on the patient for whom they were providing support, again highlighting the complexity of family systems. For example, one participant on public disability described her fear for the future when she envisions no longer being able to reside with her elderly mother:

I put myself in serious debt—like, serious debt—for someone who's on long-term disability. I owe almost \$20 000. So I've spent myself into debt. I live with my mother—who's 85, or going to be 85. I'm worried, like, "How am I going to do this?" And it's like, "I owe all of this money, my mom's going to die one of these days, I'm going to have to get out of the house." You know...I got a brother and two sisters, they're going to want money [selling the house]. You know, they've got issues, so what the \*\*\*\* am I going to do? (Patient, Intervention 4)

Mental health challenges were reported by participants across all five projects, even those initiatives not specifically targeting mental illness, and often occurred in conjunction with physical health concerns. Some patients described an awareness of the interconnectivity between their mental and physical health and how their medical conditions influenced their psychological health.

I don't know how many other people, but the mental health aspect of it [COPD] too, right? Because it's kind of depressing when you think this is going to be the rest of your life. So kind of dealing with that, too. Because, I mean...I find it played a big card for me, too, right? I

gotta get this in this peabrain that this could be, you know, this could be the new norm—so I gotta find ways of dealing with it. (Patient, Intervention 4)

### The unanticipated consequences of interventions often provide the greatest perceived benefit

Some of the main benefits patients reported through participating in the various interventions were not necessarily an explicit part of the intervention design. While the theory of change behind many of the interventions focused on education, self-management and appropriate connection to services, the primary benefits reported by patients were sometimes unanticipated consequences of these models of care. Across all projects regardless of the disease focus or population, patients stressed the importance of feeling cared for, reassurance and getting a diagnosis after lengthy periods of uncertainty.

Specifically, patient participants consistently described feeling cared for as an important benefit of the intervention and this held true across all groups. Participants described feeling grateful and comforted due to having access to healthcare services:

That's what I liked too, that everybody was on the same page...I felt like each person that spoke to me was interested in what I had to say. That's something that I wasn't used to with the other doctor. It just seemed like whatever you had to say, here's another pill. (Patient, Intervention 2)

One caregiver eloquently expressed the value of conversation and comfort she received at the end of her mother's life as being a key benefit of the intervention.

You know, it was more about how [the two doctors] talked about the end of her journey—the fact that we needed to have comfort now. It wasn't any kind of medication or anything like that; it was a conversation and I felt really good about it. (Caregiver, Intervention 1)

Patients also described receiving reassurance as a primary benefit of the educational materials they received (rather than the medical information per se). Several patients described going to the ED for help as they were anxious about their health condition, a fearfulness that they attributed to a lack of knowledge. Information and education related to community resources available to them or their caregiver was described as being particularly valuable and reassuring, as was the opportunity to receive a clear diagnosis:

I think the clinic should be mandatory because it explains things like, for example, blood clots. I thought blood clots were pieces that would form and break off but they show you a video of exactly what they are. Then you understand...It would have been nice if someone [earlier] said, "You know what? Live normally. It's not life-threatening. Don't worry about it." But I was never told that. (Patient, Intervention 3)

## Patient experiences are shaped by the healthcare discourses on medically complex patients

Many participants communicated an awareness of patients with multimorbidities as increasing the clinical burden for medical providers and as a cause of escalated healthcare costs. In describing his experiences with his physician, one patient was critical of the care he received but also refers to himself as one of the ‘crazy patients’ who are ‘complaining constantly’. In this way, he justifies the behaviour of the doctors who ‘are not even listening half the time’ through a reference to how stressed they are by a clinical workload caused by patients with multiple chronic conditions, such as himself:

They cut you off. They don't want to listen. It's incredible that you can be so damn sick and doctors are not even listening half the time. And you know what it does to you? It depresses you even more...And I don't think they mean to do it. I mean, I put myself in their position. If I had all these crazy patients coming in every day complaining constantly, like, what would I become after a while. You know what I'm saying? (Patient, Intervention 3)

Participants were also concerned about the public healthcare expenses associated with the care of their chronic conditions and worried that receiving medical care was ‘wasting taxpayer dollars’. A patient with COPD who accessed an ED because of breathing difficulties ruminated about the healthcare costs of his ED visit.

I thought, “Well, what am I doing here? I guess I'm just wasting their time. I just wasted some of my taxpaying dollars by coming here,” right? They did give me a mask and that, and sent me home, but I felt like I couldn't breathe so I came in, right? (Patient, Intervention 4)

Other participants communicated their acceptance of the system goal of reduced ED visits as the most important intervention goal. A patient commented on how having a telephone contact and resource person when symptoms worsened helped him achieve the objective of reducing costly ED usage:

Well in my case it [the 1-800 number] has kept me out of Emergency. I mean, I can think of at least two occasions when, if it wasn't here, I probably would have gone to Emerg. (Patient, Intervention 3)

## DISCUSSION

Our study findings both highlight and challenge key assumptions often embedded in complex interventions designed for patients with multiple chronic diseases. First, we identified that most patients did not like going to the ED for care and were not cavalier in their use of these services. Our data on the complex reasons patients visit the ED support the recent Canadian Association of Emergency Physicians (CAEP) statement that “the myth of ‘inappropriate use’ should be permanently dispelled”.<sup>35</sup> In general, patients viewed ED visits as a

disease management strategy of last resort that provided limited support. The ED was often utilised in crisis situations when patients and/or caregivers lacked alternative pathways to care. Further, patients were also cognisant of the financial costs associated with ED visits. While many participants reported not wanting to access emergency services due to healthcare cost and quality of care concerns, they discussed visiting the ED when no alternative options were available. This is consistent with recent studies<sup>7 10</sup> that reported the influence of structural and cultural factors on patient decision-making around the timing and frequency of ED visits.

A second key finding was the variable capacity and availability of family support systems to meet the caregiving requirements of many patients with multiple chronic diseases. This finding is consistent with the literature examining patient and caregiver careers during the trajectory of an illness<sup>13 36–38</sup> and treatment burden.<sup>38–40</sup> The assumption that patients could rely on informal support systems to negotiate and access needed services was often illusory.<sup>18</sup> Yet, unfortunately, complex intervention designs often assume that patients with chronic diseases have continuous access to a stable and caring family member living nearby (such as a spouse, child or sibling) who is able and willing to assist them with their day-to-day care and care coordination needs.<sup>38</sup> These intervention designs often presuppose the availability of informal support systems even though the impact of treatment burden on both caregivers and patients with chronic conditions is well documented.<sup>36–40</sup> Barriers to informal caregiving support included the lack of geographical proximity of family members and friends, and whether caregivers could manage the time demands of both care and care coordination. Caregiver participants, engaged as a ‘shadow workforce’<sup>38</sup> in caring for patients with multiple chronic conditions discussed not only the stresses of the caregiving role but also the paucity of available supports. In addition, some patients lacked access to strong support systems and had limited contact with family members and friends. These patients could not rely on family caregivers to support their care and care coordination needs and this reduced, in some instances, their ability to access the care they required to manage their conditions.

While the important role played by programme context and setting in the design of complex interventions has been reported elsewhere,<sup>18 41–43</sup> the findings of this study highlight key systemic elements of the patient's experience that have significant implications for care. Having access to an integrated care network of medical providers does not ensure by itself a better care experience (and probably not better medical outcomes) for patients with multiple chronic diseases.<sup>13</sup> This is largely because patients' issues and concerns are not simply medical.<sup>7 8 10 25</sup> For example, the inadequacy of social housing (including subsidised, affordable and public housing) was a major problem described by some patients. As well, participants discussed how living on a

limited income could shape patterns of care when personal finances undermined their ability to access needed food, medication and support services; there was a strong awareness among patients and their caregivers that non-medical issues were key determinants of health and healthcare utilisation—a finding that underscores the need to engage an understanding of the patients' social location, preferences and priority outcomes in the design of complex interventions. Patients were not simply lacking access to healthcare but also experienced significant challenges related to the social complexities of their lives.

A fourth key finding was that the unanticipated benefits of the intervention may provide the greatest value to patients. While participants reported that the interventions had mixed impact on the frequency of ED visits, there were often additional, unforeseen intervention rewards. A striking finding of this meta-evaluation is how much patients valued feeling cared for and the extent to which they felt this had been lacking in much of the care they had received in the past. Participants reported feeling supported and reassured through the intervention because they were in contact with individuals who listened, understood and empathised with them and validated the challenges of living with the many consequences of their health conditions. Many participants described key intervention benefits in terms of gaining greater understanding of their illnesses and symptom management approaches. The interventions were also valued by some participants because they facilitated more interactive and collaborative management of both the medical and non-medical dimensions of their illnesses.

Finally, patients and medical providers are participants in the same healthcare system and thus are shaped by similar discourses, although they might not share a common understanding of the same phenomena. The patients in our study had highly nuanced understandings of the dominant discourses on multiple chronic diseases, such as the notion that patients are a burden on their medical providers and the 'system' at large. This finding aligns with Hujala *et al*<sup>44</sup> who observe that dominant healthcare discourses on multimorbidity that emphasise escalating system costs and promote disease self-management may have unintentional effects on how patients with multiple chronic diseases are treated in healthcare and other social settings. Patients frequently described feeling guilty or ashamed for seeking services. They also excused poor care and services by attributing the cause of this inadequate care to the time pressures clinicians experience; essentially they blamed themselves for these pressures. This discourse undermines the care of patients with multiple chronic diseases and may ultimately be self-defeating if patients avoid seeking services because they see themselves as undeserving and a burden. Patients reported that they often felt alienated from their medical providers and that feeling cared for by them was the most valued benefit across interventions.

## LIMITATIONS

The primary intention of the qualitative meta-evaluation design was to capture in-depth evaluation information at the individual project level in a systematic and standardised way that would allow us to identify broad cross-cutting themes across all the projects. However, this was not always possible given the range and complexity of interventions that resulted in variability of approaches that were used in data collection. While efforts were made to standardise the interview guides, the principal investigators from each project maintained decision-making control over which questions were ultimately included. Future qualitative meta-evaluations could be managed centrally, specifying a set of key objectives, so that core elements of the experiences of patients with multiple chronic diseases can be understood across disease-specific silos. Further, not all of the project team transcripts were analysed for the purposes of this meta-evaluation as interventions were at different stages of evaluation and only transcripts that were available when we conducted our analysis could be included. The variations in data available for each project added to the complexities of analysis and did not allow us to compare the separate interventions. However, as we had achieved data saturation on the central themes we identified, we do not believe additional transcripts would have added any substantive benefit to this particular analysis as our purpose was not to conduct an evaluative comparison of projects.

## CONCLUSION

Although the influence of contextual features on complex interventions is increasingly recognised as an important aspect of design and outcome,<sup>19 21 23</sup> less attention has been paid to core elements of the patients' and caregivers' perspectives that cut across interventions, shape patterns of care and required types of support. Systemic features of the patient perspective identified through meta-evaluations can inform design improvements, implementation and evaluation of complex interventions for individuals with chronic diseases. Key assumptions about patients that underlie interventions need to be made explicit, so that intervention components can be modified as necessary. In our study, we found that underlying suppositions related to the lived nature of patient complexity, sophisticated insights into their own disease management and social context, as well as the desire to avoid ED visits could be capitalised in future intervention design to enable study success and system change that is indeed patient-centred.

Finally, our analysis also emphasises the importance of incorporating a social science lens and systems perspective to data analysis, and the value of a qualitative meta-evaluation approach in the design, implementation and evaluation of complex interventions. These findings suggest that while patients have historically been conceptualised as objects of care, they are instead active components within systems of care delivery who experience



their health concerns, healthcare and social lives simultaneously. Across many health systems internationally, multiple models are being implemented simultaneously that may have shared features and target similar patients, and a qualitative meta-evaluation approach thus offers an opportunity for cumulative learning at a system level in addition to informing intervention design and modification. Finally, including the patient perspective in qualitative meta-evaluations of complex interventions may build capacity to better understand and support patients with multiple chronic diseases.

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#### REFERENCES

1. Stumberg JP. Multi-morbidity and chronic disease: an emergent perspective. *J Eval Clin Pract* 2014;20:508–12.
2. Bower P, Macdonald W, Harkness E, *et al*. "Multimorbidity, service organization and clinical decision making in primary care: a qualitative study". *Fam Pract* 2011;28:579–87.
3. Salisbury C. Multimorbidity: redesigning health care for people who use it. *Lancet* 2012;380:7–9.
4. Guthrie EA, Dickens C, Blakemore A, *et al*. Depression predicts future emergency hospital admissions in primary care patients with chronic physical illness. *J Psychosom Res* Published Online First: 24 Nov 2014. doi:10.1016/j.jpsychores.2014.10.002
5. 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.
6. Mautner DB, Pang H, Brenner JC, *et al*. Generating hypotheses about care needs of high utilizers: lessons from patient interviews. *Popul Health Manag* 2013;16(Suppl 1):S26–33.
7. Shaw EK, Howard J, Clark EC, *et al*. Decision-making processes of patients who use the emergency department for primary care needs. *J Health Care Poor Underserved* 2013;24:1288–305.
8. Sheridan NF, Kenealy TW, Kidd JD, *et al*. Patients' engagement in primary care: powerlessness and compounding jeopardy. A qualitative study. *Health Expect* 2012;18:32–43.
9. Webster F, Rice K, Dainty KD, *et al*. Failure to cope: the hidden curriculum of ED wait times and the implications for clinical training. *Acad Med* 2015;90:56–62.
10. Hunter C, Chew-Graham C, Langer S, *et al*. A qualitative study of patient choices in using emergency health care for long-term conditions: the importance of candidacy and recursivity. *Patient Educ Couns* 2013;93:335–41.
11. Clark AM. What are the components of complex interventions in healthcare? Theorizing approaches to parts, powers and the whole intervention. *Soc Sci Med* 2013;93:185–93.
12. May C, Finch T, Mair F, *et al*. Understanding the implementation of complex interventions in health care: the normalization process model. *BMC Health Serv Res* 2007;7:148.
13. Mol A. Proving or improving: on health care research as a form of self-reflection. *Qual Health Res* 2006;16:405–14.
14. Ling T, Bardsley M, Adams J, *et al*. Evaluation of UK integrated care pilots: research protocol. *Int J Integr Care* 2010;10:pii: e056.
15. Coventry PA, Fisher L, Kenning C, *et al*. Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. *BMC Health Serv Res* 2014;14:536.
16. Kenning C, Coventry PA, Gibbons C, *et al*. Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care? *Fam Pract* 2015;32:311–16.
17. Newbould J, Burt J, Bower P, *et al*. Experiences of care planning in England: interviews with patients with long term conditions. *BMC Fam Pract* 2012;13:71.
18. Bayliss EA, Bonds DE, Boyd CM, *et al*. Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters. *Ann Fam Med* 2014;12:260–9.
19. Smith SM, Bayliss EA, Mercer SW, *et al*. How to design and evaluate interventions to improve outcomes for patients with multimorbidity. *J Comorbidity* 2013;3:10–17.
20. Mercer SW, Smith SM, Wyke S, *et al*. Multimorbidity in primary care: developing the research agenda. *Fam Pract* 2009;26:79–80.
21. Best A, Greenhalgh T, Lewis S, *et al*. Large-system transformation in health care: a realist review. *Milbank Q* 2012;90:421–56.
22. Cohn S, Clinch M, Bunn C, *et al*. Entangled complexity: why complex interventions are just not complicated enough. *J Health Serv Res Policy* 2013;18:40–3.
23. Plsek PE, Greenhalgh T. The challenge of complexity in health care. *BMJ* 2001;323:625–8.
24. Shiell A, Hawe P, Gold L. Complex interventions or complex systems? Implications for health economic evaluation. *BMJ* 2008;336:1281–3.



25. O'Brien R, Wyke S, Guthrie B, *et al*. The 'everyday work' of living with multimorbidity in socioeconomically deprived areas of Scotland. *J Comorbidity* 2014;4:1–10.
26. Payne RA, Abel GA, Guthrie B, *et al*. The effect of physical multimorbidity, mental health conditions and socioeconomic deprivation on unplanned admissions to hospital: a retrospective cohort study. *CMAJ* 2013;185:E221–8.
27. Kennedy A, Bower P, Reeves D, *et al*. Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. *BMJ* 2013;346:f2882.
28. Reeves D, Hann M, Rick J, *et al*. Care plans and care planning in the management of long-term conditions in the UK: a controlled prospective cohort study. *Br J Gen Pract* 2014;64:e568–75.
29. 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;7:147–61.
30. Wingham J, Harding G, Britten N, *et al*. Heart failure patients' attitudes, beliefs, expectations and experiences of self-management strategies: a qualitative synthesis. *Chronic Illn* 2014;10:135–54.
31. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000;23:334–40.
32. Pawson R, Tilley N. *Realist evaluation*. London: Sage, 1997.
33. Patton MQ. *Qualitative evaluation and research methods*. 2nd edn. Newbury Park, CA: Sage, 1990.
34. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
35. Affleck A, Parks P, Drummond A, *et al*. Emergency department overcrowding and access block. *Can J Emerg Med* 2013;15:359–70.
36. Kulusiki K, Gill A, Naganathan G, *et al*. A qualitative descriptive study on the alignment of care goals between older persons with multi-morbidities, their family physicians and informal caregivers. *BMC Fam Pract* 2013;14:133.
37. Sautter JM, Tulsy JA, Johnson KS, *et al*. Caregiver experience during advanced chronic illness and last year of life. *J Am Geriatr Soc* 2014;62:1082–90.
38. Bookman A, Harrington M. Family caregivers: a shadow workforce in the geriatric health care system? *J Health Polit Policy Law* 2007;32:1005–41.
39. May CR, Eton DT, Boehmer K, *et al*. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Serv Res* 2014;14:281.
40. Sav A, Kendall E, McMillan SS, *et al*. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health Soc Care Community* 2013;21:665–74.
41. Wells M, Williams B, Treweek S, *et al*. Intervention description is not enough: evidence from an in-depth multiple case study on the untold role and impact of context in randomised controlled trials of seven complex interventions. *Trials* 2012;13:95–111.
42. Lewin S, Glenton C, Oxman AD. Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *BMJ* 2009;339:b3496.
43. Tomoaia-Cotisel A, Scammon DL, Waitzman NJ, *et al*. Context matters: the experience of 14 research teams in systematically reporting contextual factors important for practice change. *Ann Fam Med* 2013;11(Suppl 1):S115–23.
44. Hujala A, Rijken M, Laulainen S, *et al*. People with multimorbidity: forgotten outsiders or dynamic self-managers? *J Health Organ Manag* 2014;28:696–712.