Beyond Multi-morbidity: Patient Perceptions of the Impact of Illness

Evidence Brief

> *"I'm going to have to change the house or sell the house because I'm going to have to have a wheelchair. My life is going to be very different when I go home. And it's going to impact both of us [patient and his partner]. "*

- A patient in his 50s with musculoskeletal conditions and infections

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

Report prepared by: Daniel Miller, Kerry Kuluski, Julia Ho and Ashlinder Gill

April 2015

Table of Contents

Executive Summary

One of the key challenges for health systems worldwide is improving services for patients with complex care needs (1-3). Studies suggest that patients with complex needs are common (4), use extensive healthcare resources (5), and tend to receive less than satisfactory care (6-9). Anyone with a chronic condition may experience significant changes in health, *over time* (10). For certain people, however, added factors push them into being *complex,* such as having more than one condition (11), functional or cognitive impairments, having limited financial resources, or limited social support (5, 12, 13).

Studies on patient complexity have tended to focus on *multi-morbidity* (12, 13), with less attention, in general, to the dynamic interplay between health and social circumstances (14). Traditional health systems, focused on episodes of acute care, are not equipped to address the major ramifications that complexity can bring to individuals and their families (e.g., stress, poor quality of life, loss of finances) as well as broader health and economic systems (e.g., rising costs and stretched resources).

In this report, we discuss findings from a qualitative study focusing specifically on *social* complexity (i.e., how illness affects the daily lives of people).The intent is to open up dialogue on what health care systems can do to better manage patient complexity. We report findings from a secondary analysis of a sub-set of interviews with adults receiving care in a Complex Continuing Care and Rehabilitation facility in Toronto, Ontario (15, 16). Complex Continuing Care and Rehabilitation is a post-acute care designation for people with high care needs who require additional support to stabilize their health before returning home. The interviews were collected originally for a mixed-methods study that explored the characteristics, needs and experiences of people in this care setting (15, 16).

In the previous study, the research team identified two themes that appeared to alter the care experiences of interviewees, giving us insight into the *social* aspects of complexity: **illness trajectory** and **life circumstances**:

1. Illness Trajectory

   First, there were differences in how recent health changes fit into patients' overall health history; specifically the distinction between stable and acute progression. Some patients had never been ill or disabled before the events that brought them to hospital prior to interview. In this report we refer to this trajectory as ***Sudden Illness***.. Other patients had already been ill or disabled for years before their current hospitalization. Their experiences of illness and disability covered extended periods of time (sometimes several years) before their interviews. In this report we refer to this trajectory as ***Ongoing Illness***.

2. Life Circumstances

   The second identified during preliminary analysis was the ***Life Circumstances*** of interviewees. The impacts of illness that patients described appeared to be related to their stage of life, social, financial, practical, and other non-bio-medical circumstances they found themselves in.

The identification of these two themes, ***illness trajectory*** (10) and ***life circumstances***, within the initial data set prompted us to ask how life impacts might look, depending on which trajectory a patient fit into, and their life circumstances at the time of their interviews. More generally, it encouraged us to consider how changes in health, patient traits, experiences and circumstances may combine to characterize the impacts of illness and disability on individual lives. This study is important given that both measurement and treatment of illness tends to focus on disease type and functional symptoms (17). **Our report offers insight into factors that should be considered when measuring and treating health in the future, particularly as an increasing number of people live longer with complex health issues (18).**

Objectives

The study had two main objectives:

1) Identify the impacts of illness among interviewees in the two illness ***trajectories*** (sudden illness and ongoing illness).

2) Identify aspects of interviewees' ***life circumstances*** that characterize the impacts of illness within and across trajectories.

Methods

The research team conducted a directed content analysis (19) of a sub-set (N=14) of in-depth interviews acquired from an initial data set (N=116). To explore the relationship between illness trajectory and life impacts, the Principal Investigator (KK) selected transcripts purposively, to explore impacts related to the two trajectory themes (sudden illness and ongoing illness) and a range of participant ages: young: 18- 44 years of age, mid-life (45-64 years of age) and older (65 years of age and above).

This resulted in 12 transcripts:

	Sudden Illness	***Ongoing Illness***
Young	X 2	X 2
Mid-Life	X 2	X 2
Older	X 2	X 2
	= 6	= 6
Initial sub-sample = 12		

After initial analysis, two additional transcripts were selected to allow further exploration of the long-term **impact of illness and disability for patients** living **with major social or financial deprivation**. **Two such additional transcripts** were selected of patients with previous, ongoing conditions. In total, <u>**14 transcripts**</u> were analyzed.

Findings

Patients in the ***Sudden Illness*** **trajectory** described impacts specific to the recent transition from healthy to ill, such as the psychological and social adjustments involved in facing long-term disabilities for the first time, and the effects on family. Patients in the ***Ongoing Illness*** **trajectory** described how life impacts had played out, or been experienced *over time*, and contributed to their current circumstances, even before recent crises.

The experiences of people within each trajectory related to their life circumstances. For those in the ***Sudden Illness*** group, thematic variations included ***functional prospects (i.e., expectations for recovery)***, ***parental obligations***, and ***differences in perspective (i.e, optimistic disposition)***. For those in the ***Ongoing Illness*** group, variations related to the specific ***characteristics of chronic conditions*** (e.g., ongoing/fluctuating conditions), the type and extent of ***previous impacts,*** and ***significance*** of a particular health crisis, relative to a patient's prior state and adaptations***.***

Three key aspects of life circumstances, ***social context***, ***aging*** and ***income security*** appeared to play a major role among patients in both trajectories.

Implications for Care Provision and Policy

The main contribution of this study is that it illustrates how the impacts of illness and disability can vary in relation to patients' life circumstances. This suggests that attending to life circumstances, and how they interact with major changes in health, may be an important aspect of care provision and health care policy. Findings suggest several implications for how health care and health policy may better meet the needs of complex patients similar to those examined here:

Recently, or suddenly, ill patients:

- Patients facing permanent, life-altering changes for the first time need psychosocial support to help them with this transition.
- Assessment of patients' obligations and responsibilities may be important so that impacts on family can be mitigated.
- Even when sudden injury or illness seems minor or non-permanent, patient differences, such as age and resiliency, may alter the severity of the impact.

Patients experiencing chronic conditions over several years:

- Psychosocial support might usefully target *chronic experiences* of isolation, frustration or hopelessness and the effects of these over time.
- It is important to continually re-assess needs, particularly after a health fluctuation/change given that previous adaptations and supports may no longer be sufficient.
- For patients living in the community, efforts should be made to limit the *fall-out* of chronic conditions over time in areas such as employment, social inclusion and housing.

Patients from both groups (sudden and ongoing illness):

- Life outside of the hospital can be characterized by social marginalization, poverty, or unhealthy living arrangements, all of which may compromise health. **Care assessments and strategies should focus on interrelated impacts in multiple domains**, such as unemployment, poverty, loss of housing and social exclusion.
- Psychosocial support for older patients may involve challenging perceptions and circumstances that make isolation and low prospects seem like an inevitable feature of illness and aging.
- Major changes in health can bring significant drops in income, as a result of limited insurance or disability coverage. **Policies should ensure that, at least for the short term after a health crisis, people have sufficient disability coverage to avoid major financial fall-outs.**

Full Report

One of the key challenges for health systems worldwide is improving services for patients with complex care needs (1-3). Studies suggest that patients with complex needs are common (4), use extensive healthcare resources (5), and tend to receive less than satisfactory care (6-9). Anyone with a chronic condition may experience significant changes in health, *over time* (10). For certain people, however, a number of factors may push them into being *complex* such as having more than one condition that requires ongoing oversight and care (11), functional or cognitive impairments, having limited financial resources, limited social support or a variety of other issues (12, 13).

When needs are complex, it is because multiple issues *interact* to create unique impacts. These impacts are *more than the sum of their parts* because they result from the *combination* of different issues. So, for example, a patient receiving two medications for two different conditions might suffer side effects brought about by this combination (6, 20). By looking at the side effects of each drug individually we don't get a full picture of the impact on the patient. When we start to think about all of the possible combinations of drugs a person might take, and the unique side-effects that could result from combining two, three, four, or more, we start to get an idea of what can make a patient's situation *complex*.

In much the same way, social or economic issues can combine with a major change in health to make a patient's situation *complex* and create impacts. For example, a patient's ability to manage day-to-day activities following a major change in health may be compromised if he or she lacks social support (21). Imagine now that the health crisis also makes the patient unable to work. Suppose he or she has no savings and now can't pay rent. Without close friends or family, he or she has no one who can offer a place to stay. With each additional challenge, the unfolding situation appears more and more *complex*. Consequently, the patient's life prospects, and the prospects of managing his or her condition, appear compromised.

One key challenge associated with complex patients is that our health and social care systems are not ideally integrated to meet their multiple, interacting and changing needs (6). The role of social determinants in shaping health has been recognized for years, but our health system still operates as if we have not learned these lessons. Issues like poor integration of health and social care services, under-resourced community care, and insufficient post-discharge follow-up, can mean that, following a change in health, a large number of impacts end up being shouldered by patients and families. Moreover, it means that potentially avoidable complications, emergencies and (expensive) acute treatments may follow.

One explanation for why our health system is not well suited to addressing the needs of social complexity is that, by and large, our vision of healthcare still excludes it. While we may recognize the importance of social determinants of health, we still think of *healthcare* in terms of bio-medical health and acute care needs. From this perspective, the interplay between social circumstances and health, over time, seems less urgent. Another way to think about it is that these issues get put on the "back burner" while more pressing emergencies are addressed. The trouble is that, too often, these important issues aren't later moved up to the "front burner". The result is that many impacts on health, and life, keep accumulating out of view, affecting the lives of patients and families, and eventually "boiling over" with another crisis.

Discussion and study about patient complexity has tended to focus on patients with multiple chronic conditions (12, 13, 22), with growing, albeit less, attention to the dynamic interplay between health and social circumstances (14). In this report, we discuss findings from a qualitative study focusing specifically on *social* complexity and its role in determining how illness affects patients' lives.

We conducted a secondary analysis of interviews conducted with adult in- patients in a complex continuing care and rehabilitation facility. Complex Continuing Care and Rehabilitation is a post-acute care designation for people with heavy care needs who require additional support to stabilize their health before returning home. These interviews were conducted for a previous mixed-methods study exploring the impacts of illness and disability on patients' lives, their healthcare experiences, and care needs (15, 16). A previous publication discussed how the impacts of illness on participants' lives extended beyond physical and functional deficits to their social lives and families, mental health, ability to participate in recreational and other meaningful activities (16).

During primary analysis, some additional themes were identified that became the focus of the secondary analysis reported here:

First, there were differences in how recent health changes fit into patients' overall health history; specifically the distinction between stable and acute progression (10). This came to be referred to as patients' ***Illness Trajectory*** in keeping with the model described by Corbin and Strauss (10). For us, two broad, contrasting illness trajectory "themes" were of particular interest: ***Sudden Illness*** and ***Ongoing Illness***.

Some patients had never been ill or disabled before the events that brought them to hospital prior to interview. Their accounts focused on the immediate or "sudden" change in health, immediate impacts, and anticipation of the future. To capture the idea that these patients were, at the time of interview, processing and coping with this drastic change, we referred to this group of patients as the ***Sudden Illness*** group**.**

Other patients had already been ill or disabled for years before their current hospitalization. Their experiences of illness and disability covered extended periods of time (sometimes several years) before their interviews. To convey the idea that their recent health crises were part of "ongoing", previous histories of major illness and disability, these patients came to be referred to as the ***Ongoing Illness*** group.

Second, the impacts on patients' lives, from illness and disability, related to their different life circumstances. In some cases, this related to patients' age or stage in life. So, for example, young parents described impacts on the ability to earn family income and raise children. Other differences like social support resources, senior status, and type of functional impairment were also identified as important to how illness and disability affected peoples' lives (or were anticipated by patients to affect them in the future). These aspects of patients' accounts were covered by the blanket category ***Life Circumstances***.

Our goal in conducting and reporting this analysis is to better understand and convey ***how changes in health may relate to, and alter, life circumstances***. By describing how illness and disability impede on, and interact with, the lives and experiences of real patients, we hope to demonstrate the intimate connection between life circumstances and health. **Our report offers insight into factors that should be considered when measuring and treating health in the future, particularly as an increasing number of people live longer with complex health.**

Objectives

The study had two primary objectives:

1) to identify the impacts of illness among interviewees in the two illness ***trajectories*** (sudden illness and ongoing illness); and
2) identify aspects of interviewees' ***life circumstances*** that characterize the impacts of illness within and across trajectories.

Methods

Selection of Interviews

An initial 12 Interviews were selected to allow the research team to explore the two central themes, ***health trajectory*** and ***life circumstances.***

Prior analysis suggested that age was a key variable related to patients' ***life circumstances***. To include interviews with patients from a range of ages, an equal number of interviews were selected from each of three age categories: ***young (18- 44 years of age); mid-life (45-64 years of age); older (65 years of age and above)***.

To explore impacts related to ***health trajectory,*** four interviews per age group were selected, across the two ***health trajectory*** themes (***sudden illness*** and ***ongoing illness***). The breakdown is as follows:

	Sudden Illness	***Ongoing Illness***
Young	X 2	X 2
Mid-Life	X 2	X 2
Older	X 2	X 2
	= 6	= 6
	Initial sub-sample = 12	

An additional 2 transcripts were later chosen to explore cases in which patients struggled with major social and financial deprivation. Both examples were of patients with ongoing illness and disability, one from the mid-life category and one from the older category. As a result, an extra interview was incorporated into the analysis of each of the *mid-life/ ongoing illness* and *older/ongoing illness* groups.

- **In total, 14 transcripts were selected for secondary analysis**

Analysis

The research team conducted a directed content analysis, aimed at testing the validity, and extending the applicability of, key constructs defined at the outset of analysis (19).
The key constructs for this study were ***health trajectory*** (10), and ***life circumstances***. Following selection of the sample, research assistants (DM, JH) each independently conducted open coding of 1 transcript, identifying major themes. Then the lead investigator (KK) from the primary study, from which the sample was drawn, met with the research assistants to consolidate the major themes into a list of 5 broad codes through consensus. These broad codes were then applied to the analysis of the remaining transcripts. Each research assistant independently coded and identified additional broad themes and sub-themes. The team (KK, DM, JH) met again to consolidate findings, resolve discrepancies and formulate a complete codebook. The final codebook was then applied to the entire set of coded data, by re-organizing codes/coded excerpts under the updated schema.

Further analysis was conducted by the lead author (DM). The two basic themes were clarified into feasible analytic categories consistent with the data and type of analysis. Subsequently, DM conducted an in-depth analysis, primarily aimed at identifying and articulating patterns within, and relationships between, the health trajectory and life circumstances. These findings are presented here in a condensed format.

Findings

All of the interviews chosen for this analysis were conducted with patients who, at the time of interview, were in hospital after a major health crisis (i.e. stroke, accidents resulting in severe fractures, an exacerbation of MS symptoms, etc.). For some, these crises had been accidents; for others the onset of previously unidentified illnesses; still others were in hospital because of complications of conditions they had lived with for years. Figure 1 on page 20 (at the end of the findings section) outlines the themes and relationships between them).

Trajectory 1: Sudden Illness

For patients in the *sudden illness* category, **the recent health crisis was the first experience of a major loss of function.** Thus, they described the immediate and anticipated impacts of this drastic change. Unaccustomed to major health problems, patients and their families struggled with the transition (temporary or long-term) from healthy and high functioning to ill and/or having compromised function. This general, or *core* theme, was a feature of all of these patients' experiences. The specific way this theme played out for different patients, however, **varied, depending on differences in their circumstances.** Here, we discuss variations related to:

- **Functional prospects**
- **Parental obligations**
- **Worldview, lifestyle and resilience**

Variation 1: Functional Prospects

The expected duration of new disabilities was an important difference between patients in this group. Some patients expected full recovery quite soon and, perhaps because of this, focused on the immediate disruption of their lives. Patients who expected long-term limitations, by contrast, anticipated more enduring impacts on their state of mind, ability to manage, or life circumstances. In the following passage, a patient describes both the recent memory of unimpaired function and the prospect of permanent disability:

> *"…it's difficult, I guess, to accept what I can do now versus remembering what I could do before. So I think that's probably one of the challenges. That is something that everyone faces. I think that would be universal – the memory of what you could do before versus what will now be your reality."*

- a patient in her 40s with a recently diagnosed neurological condition

Variation 2: Parental Obligations

For patients with children, several of the impacts they anticipated, or worried about, related to their sudden inability to fulfill roles others depended on. Two parents of young children were especially concerned about the disruption in their families' lives due to their diminished abilities to earn incomes, manage household affairs or interact with their children. One described, for example, his feelings about not being able to assist his pregnant wife with parenting duties while in hospital:

> *"But now it's hard because she's got nobody there to help back her up with the daughter. Like when the daughter gets to the point where she doesn't want to listen anymore, it's usually, "Okay, you step in," or I step in or whoever. Right? And we help each other out. And that's when it's becoming hard for her... it makes me feel useless because I can't be there to help her. But then again, I have to accept the fact that I have to get better in order to help her. And that's the hard part."*
>
> - a patient in his 30s with musculoskeletal conditions

Older parents also worried about the effects on their children, but described different kinds of impacts related to this stage of parenthood. This included concern for the emotional impact on an adult child who managed affairs immediately following his mother's major accident, and a stroke victim's concerns about providing for a high-school aged child.

Variation 3: Worldview, Lifestyle and Resilience

The impact of illness tended to vary by certain personality traits such as optimism and other dispositional characteristics. One patient (91 years old), who injured herself in a fall at home, described her accident as the sudden end of a previously healthy, happy, social, and fairly functional life. For her, the injury seemed to have permanent, life-altering implications, dividing her life into *life before* and *life after* the injury. This example suggests that an injury that might be moderate or mild in a younger patient can have major, permanent life implications when a patient is of a very advanced age. However, it also raises the question of whether major health events in older patients necessarily bring with them reduced prospects or diminished outlooks on the future.

To illustrate this point, another patient in the older group (69 years old) described similar circumstances surrounding his hospitalization, having tripped and fallen at home, severely breaking his femur. In contrast to the previous patient, this patient individual described his accident as only a temporary, albeit frustrating, interference:

> *"It's just wasted 10 weeks of my life sitting in here when I could be doing stuff. Be out and active like I've been all my life…"*

- a patient in his 60s with musculoskeletal conditions

It seems certain that the contrast between these two "older" patients relates to the large age gap between them. **However, it is unclear that it is age alone that accounts for this. Reading this second patient's interview, in particular, one wonders whether personal traits, specifically the patient's general worldview, active lifestyle or exceptional resilience did not also influence his perspective.** Drawing on his experiences in another country while a major war was happening there, the patient at one point compared the experience of being in, or witnessing, a battle, to the frustrations encountered during his hospital stay. When asked if he had experienced any stress since his hospitalization, he responded:

> *"No. Stress rolls off me like water off a duck's back. If there was a fire fight going on, okay, maybe that would be a different story."*

- a patient in his 60s with musculoskeletal conditions

Trajectory 2: Ongoing Illness

Patients in the ongoing illness group described a variety of impacts related to having lived with chronic conditions for years before their recent health crises. In contrast to the sudden illness group, **impacts had been experienced, or played out, over time, and had conditioned present circumstances.** As with ***Sudden Illness,*** experienced or anticipated impacts varied according to differences in patients' circumstances. Here we discuss variations in the ***Ongoing Illness*** theme according to:

- **Characteristics of Chronic Conditions**
- **Previous Impacts**
- **Significance of Change in Function**

Variation 1: Characteristics of Chronic Conditions

For patients with long-term conditions, recent crises were just the *most* recent in a history of major health events and part of an *ongoing* experience of being ill or disabled. Particular impacts characterized the *experience* of illness and disability over time in ways particular to patients' situations. So, for example, several comments from an older patient suggested she thought that being older *and* having an illness necessarily precluded happiness and hope for the future. Several patients discussed feelings of ongoing isolation related to mobility limitations. Some discussed the emotional implications of rapid deterioration or constant health crises, surgeries, and medication regimens. When asked what he would like healthcare providers to know about patients like himself, a patient in hospital for complications of severe rheumatoid arthritis replied:

> *"…please be patient with us when we lose our temper because it is a very frustrating life to have to live. They [health professionals] deserve respect, yes, I understand that. But every once in a while, I might be a little bit snippy."*
>
> - a patient in his 50s with musculoskeletal conditions

Variation 2: Previous Impacts

Having previous long-term conditions also means that patients' life circumstances have already changed because of them. At the time of their interviews, certain patients had experienced several major changes in social, financial, housing or other circumstances *as a result of their illnesses*. For such patients, the previous impacts of illness became influences on subsequent impacts, creating a feedback loop. One case, in particular, illustrated this. A middle-aged patient with a degenerative condition had been hospitalized after a fall at home. Instead of focusing on the injury, this patient worried about his prospects after discharge given his depression, poverty, social marginalization and sub-standard living arrangements (after intake, he ended his lease to save money, making him homeless at the time of interview). Discussing the past, he described how two initial impacts of his illness (loss of financial resources and abandonment) combined to create a third (sub-standard living arrangements):

> *"That's why I'm on Disability. I used to drive forklift trucks and now my balance is off so I couldn't do my job anymore... I had a 20-year relationship with a woman. And when I got diagnosed with [degenerative condition], she said bye-bye… she asked me to leave... So I took the first place I could find, which was some dump…"*
>
> - a patient in his 50s with a degenerative condition, infections and depression

Variation 3: Significance of Change in Function

Having previous experience facing the challenges of chronic illness and disability means that patients may have already made adaptations. Even if these were successful in the past, the prospects of adapting after a *new* health crisis depend on how and how much a patients' function and needs change, when compared to the past. For some patients, a long period with relatively little change can mean that adaptations are effective for a long time. One older patient, for example, lived for decades in a house specifically built by her husband for wheelchair access, shortly before she lost the ability to walk (after the onset of a degenerative condition). Thirty years later, the design was still sufficient. Even though, when interviewed, this patient had recently had a leg amputated after a life threatening infection, there was no additional major change in her mobility (because she had already relied on a wheelchair for decades).

By contrast, another patient with long-standing mobility limitations had, nevertheless, been able to walk using a walker until his recent health crisis. Because of a series of complications related to his condition, this patient believed he would no longer be able to walk and would require a wheelchair after discharge. Hence, the previously sufficient adaptations would be significantly strained or overwhelmed:

> *"So [my car is] just the right height to get in easily without having to lift myself up or to climb up. I sort of just sit down like it's a chair. And just get myself in and out. The biggest trick now is, now that I'm confined to a wheelchair, is I have to get my partner to help me get in and out, and put the chair in the car and all that sort of thing. It makes it much more frustrating but it still can be done."*
>
> - a patient in his 50s with musculoskeletal conditions and infections

Common Themes

Social Context

Patients found themselves in a variety of social circumstances at the time of their interviews. In some cases, it seemed clear that these were the result of previous health changes. In other cases, however, people's social circumstances looked the way they did for other reasons. For a much older patient, abuse and neglect at the hands of a younger relative were implicated in her malnourishment, dehydration, poor hygiene, and an unhealthy living environment. Divorced and without children, she described herself as having no friends (they had all died). While her dependence on an abusive relative was in part a consequence of chronic impairments and age, her harmful social context appeared to have deeper roots:

> *"Well, I'll tell you, I have never been treated very nicely in my life. My mother was terrible to me. My mother was a rotten...No, my mother was terrible to me. I'm telling you… She'd take rushes at me. That cane I've got in my room, I hate the look of it because you know what, she hit me with that every day. My backside was as black as your blouse. It wasn't just blue, it was black…. I've been abused an awful lot with my mother and him [younger relative]. My mother, she died. I never even dropped a tear. And then along come [younger relative]."*
>
> - a patient in her 80s circulatory and pulmonary conditions

Regardless of a patient's trajectory into illness and disability, social support varies greatly because of many factors, such as the characteristics and resources of one's family and its members. One patient, in stark contrast to the previous example, benefited from robust and consistent support after an accident. She attributed much of her recovery to this. The patient described supporting one another as basic to her family's ethos. She and her siblings had grown up just assuming that that is what family does. She also benefited from particular skills of family members describing, for example, how her brother, an architect, was building an apartment unit specifically for her needs in anticipation of discharge. This feature of the patient's circumstances stood to limit the negative impact of her health crisis by solving a major practical problem for her.

Just as the roles played by family members and friends determine social context, so too do the roles played by patients themselves. The fact that a person has a major chronic condition does not mean that they do not play an essential role in their families, and may have for a long time. For “ongoing” and “sudden” patients alike, a major change in health or function can mean a major reduction in this role. As a result, a family’s ability to adapt, both in general and *to that very change* can be compromised. A middle-aged patient, for example, described herself as the proactive decision maker in her marriage. Fatigued, bed-ridden and in hospital, she worried that key decisions would not be made by her husband. She felt that their long-term marital dynamic would be a hindrance to adaptation:

> *“And I don’t think it’s a good model for marriage, where you're just taking over from somebody and making the decisions but on some things, I’ve just had to do that so that they get done. Especially for the kids when they were little. Anyway so that’s just the way it is. This morning when I tried to talk to my husband again about the [need to sell the house], his eyes just glazed over. So what am I going to do? That’s my big source of fear for me now. What am I going to do?”*

- a patient in her 50s with musculoskeletal conditions

Aging

Aging (i.e. being or becoming a senior) was a major theme in interviews with the three oldest patients in the sample. For two patients (one from each trajectory), aging and illness/disability were described in terms of long-term or sudden, *permanent* reduction in life prospects. For a 91 year-old patient who fell at home, this was described in terms suggesting her age set her up for a poor recovery and, consequently diminished her life prospects fairly suddenly. For an 80 year old patient, originally hospitalized for a diabetic foot ulcer, description focused more generally on the impossibility of happiness when aging with illness and disability. In both cases, patients’ accounts suggested feelings of limited future prospects, specific to being ill or disabled *while being older*.

Despite their feelings of limited prospects, both of these patients benefited from the support provided by their adult children. However, a third patient (89 years old) did not have any children, nor did she have any other form of reliable social support. As discussed above, an abusive social context was strongly implicated in the state of her health prior to hospitalization. However, the fact that she was *dependent on* an abusive relative was also a function of her age, independently of her impairments. **Because of her age, she had simply lost her friends and others who cared about her**:

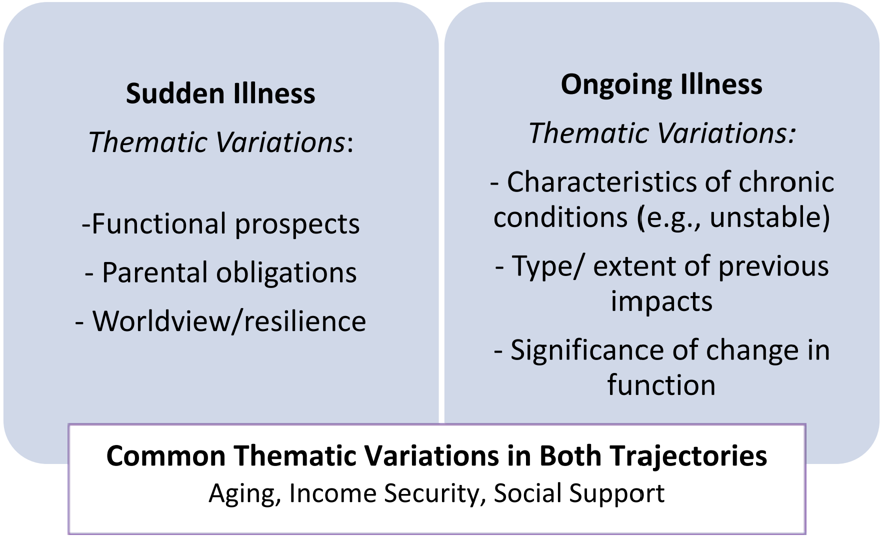
> *"See all my friends are dead and I was older than them…. my brother-in-law, he was awfully good to me when my sister died… My sister died first and then he died."*

- A patient in her 80s with circulatory and pulmonary conditions

Income Security

Patients from both categories (sudden and ongoing illness) described financial fall-outs, which differed depending on whether they had sufficient financial resources. Patients above sixty-five were all pensioners and, perhaps in part because of this, described fewer financial impacts of their recent health crises. Patients under this age, however, varied in their levels of financial security. More specifically, those who were self-employed or did not have employer subsidized insurance plans seemed to be impacted the most. Regardless of *how* someone obtains a disability or whom they happen to work for, a major cut in income could not happen at a worse time than when they are struggling with the effects of a major downgrade in health and function. Although developed countries offer some level of publicly insured services (e.g., hospital and physician care), ongoing needs among this population often extends beyond what is publicly insured, and those who do not have adequate private insurance coverage may be burdened with substantial out-of-pocket costs. Ensuring that all patients have sufficient financial resources *at least* for the short to mid-term after onset and discharge would seem to be both a medically and economically wise strategy.

Figure 1: Trajectories and Health Impacts



Implications for Care Provision and Policy

In this secondary analysis of interviews with complex in-patients, we took a close look at the relationships between different aspects of patients' lives, the trajectories of their illnesses, and life impacts. Most significantly, we identified variations in patients' life circumstances related to how illness and disability played out, or were experienced.

Although this analysis focused on a small group of patients, it suggests some general implications for how chronic illness and complexity are understood and addressed. By articulating how different aspects of individuals' lives may relate to their health, we get an idea of how the interplay between health and life circumstances can look. In this way, some important chapters in these patients' stories have been uncovered.

A major implication from this study is that broad demographic categories (for example age groupings) or patient 'typologies', while important dimensions of analysis, provide an incomplete picture of the needs of individuals. At the level of populations with complex care needs, this is an important insight because patient-to-patient variation, (specifically a large number of different combinations of medical, functional, or social factors) is great. In a single person, a large number of variables intersect to influence just how a change in health (whether gradual or sudden) affects his or her life. In this way, *social* complexity is similar to *medical* complexity; multi-morbidity in particular, in that individual needs tend to defy standardized models (5, 1). Our study simply shows how specific patient experiences can fall within broad themes, but also divert from them in important ways.

Rather than just making their lives, and healthcare provider's lives, more *difficult*, the variations that make patients complex also suggest *opportunities* to improve their care. The challenge, then, for health providers, policy-makers and researchers, is incorporating these considerations into the dynamic world of healthcare, where providers are faced with the (often urgent) needs of individuals they come into contact with. How can these points of contact be turned into opportunities to address social complexity and thereby influence future trajectories for the better?

Broadly, this involves a major shift in attitudes about health and the organization of health care, and the adoption of strategies that address the interplay between health and social issues. The relevance of life circumstances to health, and health issues to life circumstances needs to be built into the ways different sectors can and do interact. This involves clarifying, communicating and acting on the "health arguments for social services" and the "social arguments for health services".

Drawing specific policy or programming implications from an analysis of fourteen interviews needs to be done with caution and modesty. Qualitative studies can make a contribution, but wide scale strategies, need to be based on understanding of population health patterns. However, the findings from this study suggest specific strategies that may be relevant to the thematic relationships found here.

Recently, or suddenly ill patients:

- **Patients facing permanent illness and disability for the first time may require psychosocial support in transitioning** to a new sense of identity, negotiating interpersonal interactions, and developing new strategies to build and maintain social ties.

- **Assessment of patients' obligations and responsibilities may help to inform strategies aimed at minimizing impacts on family.** Transitional supports, ideally, would also be provided to patients' partners and families to minimize temporary disruptions and aid in adaptation to long-term changes. Providers might assess, together with patients and loved ones, preexisting strategies for adaptation, immediate and likely impacts of major health changes, and the development of new, or adjusted, strategies.

- **Even when sudden injury or illness seems minor or non-permanent, there is no 'standard' experience of a particular health event. Experiences may differ depending on characteristics that can complicate recovery,** such as being much older, or characteristics that influence how impact is *perceived*, like general worldview or past experiences.

Patients experiencing chronic conditions over several years:

- **For patients living in the community, efforts should be made to limit the *fall-out* of chronic conditions over time.** Acute focused health care systems that are financially constrained are ill suited to the management of conditions that have a gradual onset. Over time, even just a few years, a person's physical, emotional, social and financial circumstances can change drastically. Projecting the likelihood of such fallout, and following up regularly may thus be crucial in preventing unemployment, social marginalization, poverty, and sub-standard living conditions. Given the importance of these issues to health, offering services based on these projections should be thought of as a health strategy.

- **It is important to continually re-assess needs and the availability of resources, particularly after a health fluctuation/change given that previous adaptations and supports may no longer be sufficient.** Projecting the practical impact of a health event involves looking at a change in function relative to the adaptations and resources a patient has.

Patients from both groups:

- For some, life outside of the hospital is characterized by social marginalization, poverty, or unhealthy living arrangements, all of which can compromise health. **These circumstances can arise for a variety of reasons, including previous health problems. Care assessments**

and strategies should perhaps focus on interrelated impacts of illness in multiple domains, such as unemployment, poverty, loss of housing and social exclusion. Anticipating, and intervening to prevent such impacts, or to create *lasting* changes when they are already present, may be essential for effective post-discharge care planning. **Community-based care strategies might be most effective and efficient if they targeted multiple areas of need (e.g. financial, housing, social support) in a coordinated manner. Subsidized supportive housing is one example of this kind of strategy.**

- **In designing and providing supports, there should be some focus on patients' specific social contexts**, for instance the type, quality and variety of informal supports available to them, and the role they play in their families. This may involve buoying informal supports to increase their capacity, filling in where they can't, or reducing strain on care providers.

- **Psychosocial support for older patients may involve challenging the perceptions and circumstances that make isolation and low prospects seem inevitable.** This might involve removing barriers to participation in community or facilitating cherished pursuits. It might also involve simply visiting a patient regularly to check in and talk. Much older patients without children or spouses may be in particular need of this kind of care and particularly vulnerable when it is absent. This may involve assessment and intervention focused on how patients think and feel about aging, the way it relates to illness and disability, and how changes in health create *specific* impacts on the ability to derive meaning and joy from life. Bolstering the capacity of the community support sector to provide friendly visiting, adult day programs, dining clubs, transportation services, and other social supports that organically (and strategically) emerge in the communities of older adults are needed.

- Major changes in health can bring significant drops in income, as a result of limited insurance or disability coverage. This is a major source of stress at a time when patients need to focus on recovery. People need income security, *particularly* when dealing with a health crisis. **Policies should ensure that, at least for the short term after a health crisis,**

people who don't have access to employee benefits have sufficient disability coverage to avoid major financial fall-outs.

Next Steps

Based on this analysis our team has developed a series of aggregate "case examples" (aka: vignettes) that illustrate a range of illness experiences and impacts described in this report. These vignettes were presented to health professionals, whose feedback was used to refine them, incorporating their challenges, knowledge and perspectives, as care providers for people with complex care needs. In the next phase of research, the team will present these vignettes to a range of health and social care providers who will then design and build packages of services that aim to meet the needs of the people represented in them. Given the level of social complexity in the vignettes, we believe that the packages of service may extend beyond what traditional health care systems currently provide which will have important implications for future service design and delivery. The goal is to eventually test the recommended models of service in real practice settings.

References

1. Moineddin R, Nie JX, Wang L, Tracy CS, Upshur RE. Measuring change in health status of older adults at the population level: the transition probability model. BMC Health Serv Res. 2010;10:306.
2. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition--multimorbidity. JAMA. 2012;307(23):2493-4.
3. Lyons R, McIntyre L, Warner G, Alvaro C, Buchan A, Reckless I, et al. Chronic illness research: Translating what we know into what we do. In: Kralik D, Paterson B, Coates V, editors. Translating chronic illness research into practice. Oxford: Blackwell Publishing Ltd; 2010. p. 163-97.
4. Tinetti ME, McAvay GJ, Chang SS, Newman AB, Fitzpatrick AL, Fried TR, et al. Contribution of multiple chronic conditions to universal health outcomes. J Am Geriatr Soc. 2011;59(9):1686-91.
5. Rosella LC, Fitzpatrick T, Wodchis WP, Calzavara A, Manson H, Goel V. High-cost health care users in Ontario, Canada: demographic, socio-economic, and health status characteristics. BMC Health Serv Res. 2014;14:532.
6. Boyd CM, Fortin M. Future of Multimorbidity Research: How Should Understanding of Multimorbidity Inform Health System Design? Public Health Reviews. 2010;32(2):451-74.
7. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. The Lancet. 2012;380(9836):37-43.
8. Salisbury C. Multimorbidity: redesigning health care for people who use it. Lancet. 2012;380(9836):7-9.
9. Burgers JS, Voerman GE, Grol R, Faber MJ, Schneider EC. Quality and coordination of care for patients with multiple conditions: results from an international survey of patient experience. Eval Health Prof. 2010;33(3):343-64.
10. Corbin JM, Strauss A. A nursing model for chronic illness management based upon the Trajectory Framework. Sch Inq Nurs Pract. 1991;5(3):155-74.
11. Nelson MLA, Kelloway L, Dawson D, McClure A, McKellar K, Menon A, et al. Stroke rehabilitation and patients with multimorbidity: a scoping review protocol. Journal of Comorbidity. 2015;5:1-10.
12. Schaink AK, Kuluski K, Lyons RF, Fortin M, Jadad A, Upshur RE, et al. A scoping review and thematic classification of patient complexity: Offering a unifying framework. Journal of Comorbidity. 2012;2(1):1-9.
13. Safford MM, Allison JJ, Kiefe CI. Patient complexity: more than comorbidity. the vector model of complexity. J Gen Intern Med. 2007;22 Suppl 3:382-90.
14. Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. J Clin Epidemiol. 2012;65(10):1041-51.
15. Kuluski K, Hoang SN, Schaink AK, Alvaro C, Lyons RF, Tobias R, et al. The care delivery experience of hospitalized patients with complex chronic disease. Health Expect. 2013;16(4):e111-23.

16. Kuluski K, Bensimon C, Alvaro C, Schaink A, Lyons R, Tobias R. Life Interrupted: A qualitative exploration of the impact of complex chronic disease on the daily lives of patients receiving complex continuing care. Illness, Crisis & Loss. 2014;2(22):127-44.
17. Upshur R, Kuluski K, Tracy CS. Rethinking Health Outcomes in an Era of Multimorbidity. Toronto, Ontario: Healthy Debate; 2014.
18. Salive ME. Multimorbidity in older adults. Epidemiologic reviews. 2013;35:75-83.
19. Hseigh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. Qualitative Health Research. 2005;16(9):1277-88.
20. Upshur RE, Tracy S. Chronicity and complexity: is what's good for the diseases always good for the patients? Can Fam Physician. 2008;54(12):1655-8.
21. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J, et al. Social networks, social capital and chronic illness self-management: a realist review. Chronic Illn. 2011;7(1):60-86.
22. Mercer SW, Smith SM, Wyke S, O'Dowd T, Watt GC. Multimorbidity in primary care: developing the research agenda. Fam Pract. 2009;26(2):79-80.

Acknowledgements

The authors acknowledge the Ontario Ministry of Health and Long-term Care, Health System Performance Research Network Grant for funding the research presented in this report. The views in this report reflect those of the authors and not the funder.