

# PRIORITIZING ILLNESS: LESSONS IN SELF-MANAGING MULTIPLE CHRONIC DISEASES<sup>1</sup>

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*Abstract.* Chronic disease management strategies are typically based on single disease models, yet patients often need to manage multiple conditions. This study uses the concepts of “chronic illness trajectory” and “biographical disruption” to examine how patients self-manage multiple chronic conditions and especially how they prioritize their conditions. Fifty-three people with multiple chronic illnesses participated in one of six focus groups. The results suggest that people who were disrupted tended to be younger than 60, lived on their own, cared for other family members, or encountered other barriers. Many people anticipated subsequent illnesses because of their age and prior experience with illness. Their reasons for prioritizing a particular illness included: (1) the unpredictable nature of the disease; (2) the condition could not be controlled by medication; and (3) the condition set off other health problems. Social context played a key role in shaping patients’ biography and chronic illness trajectory.

**Key Words:** self-management, self care, chronic illness, comorbidity, biographical disruption, sociology of health

*Résumé.* Les stratégies chroniques de direction de maladie sont principalement fondées sur les modèles de maladie seuls, pourtant les malades ont souvent besoin de gérer des conditions multiples. Cette étude utilise les concepts de ‘la trajectoire de maladie chronique’ et ‘l’interruption biographique’ examiner comment des malades gèrent automatiquement des conditions chroniques multiples et surtout comment ils prioritaire quelle condition recevra la plus grande attention. Cinquante-trois gens avec les maladies chroniques multiples ont participé dans un de 6 groupes de foyer. Les résultats suggèrent que les gens qui ont été interrompus aient eu tendance à être plus jeunes que 60, habité a seul, soigné les autres membres de famille, ou les autres barrières. Beaucoup de gens ont prévu des maladies subséquentes données leur âge et leur expérience préalable avec la maladie. Leurs raisons pour priorité une maladie particulière a inclus: (1) la nature imprévisible de la maladie; (2) la condition ne pourrait pas être contrôlée

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par les médicaments; et (3) la condition a eu tendance à déclencher le reste de leurs problèmes de santé. Le contexte social a joué un rôle clé dans le moulage de malades la biographie et la trajectoire de maladie chronique.

**Mots clés:** conditions chroniques, moi soin, co-morbidity, la trajectoire de maladie chronique, l'interruption biographique, sociologie de santé

## INTRODUCTION

Chronic disease is now the leading cause of death in developed countries. The burden of chronic illness is magnified because many chronic conditions often occur as comorbidities (Bayliss et al. 2003), which is linked with increased mortality and use of health services, decreased quality of life, and patient's ability to self-manage their health (Childs 2007; Gately et al. 2007). Although health professionals offer advice and support, most of the burden of managing multiple chronic illnesses falls on patients and their families (Kerr et al. 2007).

Disease management strategies are often based on single disease models or chronic disease generally (Barlow et al. 2005), yet patients often need to manage multiple conditions simultaneously. Relatively little is known about how patients self-manage multiple chronic conditions and especially how they *prioritize* which of their health problems will be given the greatest attention (Childs 2007; Kerr et al. 2007). Developing a better understanding of how patients self-manage and prioritize comorbid conditions can offer insight into how disease management strategies might more effectively incorporate comorbidity. This study adds to the sociology of health care literature by building on Bury's (1982) concept of "biographical disruption" and Corbin and Strauss's "chronic illness trajectory" and examining the extent to which they apply to patients managing multiple chronic conditions.

## THE SELF-MANAGEMENT OF CHRONIC DISEASE

Self-care is a major component of chronic disease management because the majority of illness management takes place outside of formal care (Gately et al. 2007). Having multiple chronic illnesses can influence a patient's ability to self-manage their health (Childs 2007; Lindsay 2008). Although little is known about the process of self-managing multiple chronic illnesses, several studies have examined the barriers that patients experience in doing so. For example, barriers often include interaction effects of conditions and medications (Bayliss et al. 2003), difficulty

following recommended exercise and dietary plans (Krein et al. 2005), depression, fatigue, poor communication with physicians, lack of social support, pain and physical symptoms, financial problems, lack of awareness, and transportation problems (Jerant et al. 2005). The burden for self-management is heavy for people with multiple chronic conditions.

The number of chronic diseases a person has is often linked with the presence and severity of disability. Thus, comorbidities can have a profound impact on a patient's ability to manage health problems (Piette and Kerr 2006). For example, depression and arthritis can hinder a patient's functioning and even pose barriers to lifestyle change (Krein et al. 2005). Comorbid conditions may create competing demands on a patients' self-management resources (Kerr et al. 2007), yet little is known about how patients prioritize what illness they focus their greatest attention on.

Past studies focus on counts of diagnoses as a means of capturing the effects of comorbidity (Piette and Kerr 2006). Limitations with this approach are the assumptions that all comorbid conditions have a similar effect and that patients manage according to the number of conditions that they have. Although such approaches can capture the overall burden of illness (Piette and Kerr 2006), they cannot identify *how* patients manage and prioritize their illnesses. Understanding how patients prioritize their health may provide insight into their adherence to self-management tasks and disease-specific interventions (Piette and Kerr 2006).

### *Theoretical Approach*

The link between health and adaptation to multiple chronic illnesses can be understood through the constructs of Corbin and Strauss's chronic illness trajectory model along with Bury's concept of biographical disruption. Some sociologists have used the concept of "illness career" to portray the continuum of health care (Goffman 1961; Hughes 1971). An expansion of this concept is the theoretical framework of illness trajectory, which refers to the course of an illness over time and actions of patients, families, and health care providers to manage that course (Corbin and Strauss 1988; 1991). The course of a disease or its "career" can be influenced by medical, social, political, economic, biographical, and psychological forces (Wiener and Kayser-Jones 1990). Even though a disease may be the same physiologically, each individual's trajectory is different and takes into account the different circumstances of each individual (Jablonski 2004).

Corbin and Strauss's (1991) trajectory model refers not only to the physiological signs and symptoms of the disease but also what people do to cope with the disease. People often experience a biographical disrup-

tion as they begin to cope with the implications of the diagnosis. Over time the course of chronic conditions tends to vary as symptoms increase and decrease. The value of this framework is its focus on social context. Its value for this analysis lies in the interaction with external micro- and macro sociological conditions (Wiener and Kayser-Jones 1990).

Illness is often placed within a biographical context (i.e., what had been going on before, what life was like in the past, what hopes were interrupted or changed (Corbin and Strauss 1988). Bury's (1982) concept of biographical disruption (referring to the taken-for-granted assumptions and behaviours in terms of both the body and in the social context of individual's lives, especially the meaning and response they have to any disruptions) is useful for understanding the impact of chronic illness on one's life. Biography refers to conceptions of self that evolve over the course of biographical time and arise directly through social context or indirectly through the body, working together to give one structure and continuity at a point along the biographical time line. An illness often throws these elements into disequilibrium (Wiener and Kayser-Jones 1990). Bury argued that the onset of chronic illness disrupted a person's life, creating uncertainty and, thus, leading them to rethink the world around them. Bury (1982) outlined three aspects of disruption: (1) the disruption of assumptions and behaviours; (2) the disruptions in the person's biography and self-concept; and (3) responses to the disruption and the mobilization of resources.

This study adds to the sociology of chronic illness by examining the extent to which biographical disruption and illness trajectory apply to patients managing multiple chronic conditions. Most of the focus on biographical disruption and illness trajectory has been on single diseases. Relatively little is known about the process of self-managing multiple chronic illnesses and patient's movements along the illness trajectory.

## **METHODS**

The objective of this paper is to develop a better understanding of how people with multiple chronic illnesses prioritize their various conditions. The data for this research was drawn from a larger study (Lindsay et al. 2008) of a health portal's influence on the self-management of heart conditions. The overriding aim of this nine-month trial was to test whether facilitated access to an Internet health portal could improve the capacity of men and women with heart disease to manage their own heart conditions. Given the extent of comorbidities in this sample, qualitative data was also collected alongside the trial.

### *Data Collection and Participants*

This randomized controlled trial in the larger study drew a sample ( $n=108$ ) of men and women aged 50–74 from GPs' coronary heart disease (CHD) registries in Greater Manchester, UK (Lindsay 2008). The study received ethics approval from the University of Manchester and from the local Primary Care Trust. Of the 108 people, 69 patients had more than one chronic condition. Each person was sent a letter asking if they would be willing to take part in this additional element of the study. A total of 53 people agreed to take part: 51 people participated in a focus group on the topic of managing multiple chronic conditions, and 2 were interviewed separately (lasting 2–2½ hours) due to scheduling conflicts. Six focus groups of 6–10 people were conducted in March 2007. Groups were selected primarily on age and gender (three focus groups including men: two with those aged 60+ and two with younger than 60; and three focus groups with women: one with those aged 60+ and two with those younger than 60. Each focus group lasted an average of 2 hours. The sample comprised 29 males and 24 females. The average age was 62.8 years. The average number of conditions was 3.3, ranging from 2–8.

The focus groups asked participants to describe their illnesses, the order in which they occurred and how they prioritized their conditions. Participants were asked to describe what a typical day was like for managing their conditions and especially the strategies they used to cope. They were then asked what advice they would offer to others who suffer from multiple chronic conditions and any barriers or limitations in managing their illnesses. Although this was a semi-structured format participants were encouraged to talk freely about their experiences. Focus groups are particularly useful with older people, especially those who are chronically ill and may have traditionally been excluded from other forms of research (Bowling 1999). As an exploratory analysis, focus groups were an effective method for obtaining rich data where the participants could build on one another's responses (Asbury 1995; Kroll et al. 2007). Focus groups can also identify and explore the range of experiences in a sample (O'Donnell et al. 2007).

### *Analysis*

Each participant's demographic details and health status were drawn from the baseline data and longitudinal surveys of the larger project. The focus groups and in-depth interviews were tape-recorded and later transcribed verbatim. They were then sorted, coded, and categorized with the aid of NVivo, a qualitative data analysis program (Richards 1999). The project drew on interpretive traditions within qualitative research where an in-depth understanding of the participants' experiences was

developed. The analysis began by reading through each transcript several times and noting emerging themes and patterns. Participants were encouraged to speak one at a time to ease identification during the analysis of the transcripts. The researcher already knew all of the participants beforehand and was able to identify who said what during the meetings.

## RESULTS

Having multiple chronic illnesses was central to these people's biography; however, only about half of participants considered their biographies disrupted with the diagnosis of a subsequent illness. In most instances, these were people who were younger or who encountered barriers in managing their health. Several people in this sample anticipated an additional illness mainly because of their age and/or pre-existing conditions. Most participants attempted to normalize their illnesses by prioritizing their "main" condition. This helped them to cope with their health problems and stabilize their health.

### *Reaction to Subsequent Diagnosis*

There were three main types of reactions to subsequent diagnosis of a chronic disease: (1) those who anticipated the illness; (2) those who were not expecting it but accepted it as part of their illness trajectory and (3) those who were in complete shock and unable to come to terms with it. For the first two categories of people their hopes were not really changed given past experience with illness and uncertainty. With the third category, patients experienced great interruptions to their biography and had difficulty coping.

### **Anticipated**

Those who anticipated subsequent illnesses tended to be male, married, and/or had more health problems. Perhaps the role of social support that is received in a marriage helped men to cope better with a new diagnosis. Those with more health problems may have developed better coping skills for dealing with illness.

Although many participants described being shocked and somewhat upset by the diagnosis of their first illness, this was often not the reaction for subsequent illnesses. This may have resulted from patients viewing their illness as part of the aging process and/or linked to a condition they already had. For example:

The way I look at it, actually, I'm 74, I've gone past my life expectancy so anything else is a bonus. I still play the drums. I just carry on normally as I did before except I can't walk as fast as I used to. (1-2)

Several others discussed how they had certain illnesses within the family (especially heart disease) and thus, were not the least bit surprised when they were diagnosed. The patients who were more accepting of a new diagnosis did not seem to throw their biography into disequilibrium, which may be a function of age and prior illness (coping) experience. Many of them had a strong self-concept that was already shaped through the course of illness allowing patients to cope despite the diagnosis of a new illness.

### **Acceptance**

Those who were more accepting of subsequent diagnoses were typically married, over 60 years old and tended to have good coping skills. Patients often came to terms with their declining health but wanted to keep their conditions as stable as possible and live within the limitations of their illnesses. For example:

You think, well, it's another bump in the road. You get over these things and something else comes along. (2-1)

Other participants simply accepted that being ill was part of the aging process:

By the time you get to 65 you have 2 serious things wrong with you. I've beaten the averages. (4-2)

Welcome to the joys of growing old. (6-2)

Patients often tried to reframe the meaning they assigned to activities and modified how they performed them to keep their illnesses stable. One man with arthritis, diabetes, and heart disease said

You'll never be what you were before that illness was diagnosed. The faster you accept it the faster you can get moving on with your life. Within the limitation of my illness I try to make the best of it. (5-3)

He was upset at first because he had to retire early as a result of his health problems. Instead of dwelling on what he could no longer do he decided to volunteer for a local football team. This maintained his sense of self worth because he was still applying his skills and felt valued by others.

A consistent theme was the importance of stabilizing the illnesses. Several people spoke of trying to remain positive to fight off depression:

you can lie in bed and say 'I can't do anything because I'm ill.' Or you can make the most of what you do have. (2-3)

This particular man described how he did not want to give up golfing because of his health problems. He got himself a golf cart and limited

the number of holes he played — showing his determination to continue to live normally.

Several people said it was essential to keep a routine going, to keep busy, and especially to keep your mind active.

The days you get depressed are the days that you don't want to do anything. You feel tired and drained but you've got to make yourself do something. You can sit in bed and watch telly or you can go out and do something. (6-3)

I think it's important to look for what you can do and not be obsessed about what you can't do. (2-3)

You have to make the most of it. (7-3)

I think you can't let it get you down. You can't think, I've got it. Tough that's my bad luck. You have to do as much as you possibly can. (1-3)

Many agreed that minimizing depression was important, even before prioritizing other health problems. Most people tried not to dwell on their health problems and instead just tried to keep on living their life as normally as possible. Some emphasized the importance to view themselves as "normal" and not as someone with an illness. Some discussed how they paced themselves to help maintain normality and come to terms with their illnesses:

I realize that if I overdo things physically then I'm going to have to pay for it the next day. I'm going dancing tomorrow night, salsa. I'll go out in the morning. I'll come home mid-day, rest in the afternoon, and I'll go out in the evening and enjoy myself. I can't dance all night like I used to be able to though. So what I'll do is I'll have a couple of dances. Sit and rest then have a couple more. (2-5)

You balance it out then. (3-5)

I do jazz. (5-5)

I like salsa. (2-5)

At least you're doing it and you are still going. I know some people who say, oh I can't do this, and I can't do it. So they don't even attempt to do it. (6-5)

Another man described how it was essential not to dwell on the things you could no longer do.

It's very important to try and thread your way through things looking for the ways that you can do them. Don't get overburdened with the things you can't do. (3-3)

Keeping their illness stable was important to prevent further health problems and to maintain normality. People who were more accepting of their recent diagnosis often had more social support, particularly from their spouses and children and may have been better able to mobilize resources to effectively manage their illness.

### **Unstable/crisis phase**

Many of the participants felt disrupted with the diagnosis of a subsequent illness and this topic generated a lot of discussion within the focus groups. Although most of the participants experienced an unstable period or crisis with their health problems at some point, there were several people who seemed to be in this phase for much longer than others. Such people were often younger than 60, those who lived on their own, or had encountered barriers in managing their health. For example, men and women under 60 were particularly distressed as they often had to give up work because of their health problems.

I used to do a lot but I can't now. It's unbelievable. I just don't understand it. I think I'm still young. I miss my colleagues. (7-4)

Younger patients seemed to encounter greater uncertainty (and biographical disequilibrium) as their hopes for the future were often interrupted. They were often in shock that they became ill so young and often focused on what life was like before, especially their working lives. Some younger people became depressed when they found out they could no longer work because their routine was disrupted and they had not anticipated retiring that young. Such a diagnosis often took them off guard and threw their illness trajectory off course.

It's very hard not to be able to do what you want to do when you're not that old. I was working one day but not the next. (8-4)

I'm even younger and it's even harder for me. (2-4)

It's unbelievable to me and the more I think about it the more upset and angry I get because I'm only 60. (7-4)

Having to stop work earlier than planned frequently disrupted biographies with feelings of guilt and depression, not only because their daily routine changed but also because they no longer felt useful. Without the social support of their work colleagues to draw upon, they likely lacked the resources necessary to cope with illness.

Several people who lived on their own found it difficult to manage multiple conditions. A widowed man describes his situation:

All of these things are magnified because I live alone. I'm a widower and

the nearest member of family is 120 miles away. If it's got to be done you've got to do it. (9-1)

Lacking support from others can shape a patient's illness trajectory because it can hinder the extent to which daily activities (especially those related to maintaining health) are performed. Several people described how they coped well in the past when their partner was able to help them.

One single woman who managed her kidney disease very well describes how upset she was, not because she found out she had heart problems, but because her heart attack worsened her kidney disease:

The doctors said that the heart attack had accelerated the kidney condition. That was big tears then. I'd not cried up 'til then. They more or less said I was going on dialysis then. (3-6)

Coming home from the hospital to an empty house was not an easy task. She was upset because she could no longer manage her kidney disease effectively at home; now she needed dialysis three times a week. For her it was coming to the realization that she could no longer manage by herself and in her own home. It was not that she was not ready to accept living within the limitations of the severity of her conditions but rather how she was going to cope with transportation to and from hospitals and the time constraints imposed on her fairly active and busy life. This put her illness trajectory in an unstable mode as she felt uncertain of how she would cope.

Those who cared for others (either dependent children or an ailing spouse) often encountered greater difficulty in stabilizing their illness. They often discussed how their symptoms were secondary compared to meeting the needs of others within their family. Some discussed caring for a spouse who had even more disabling conditions than they did, so they did not have time to manage their own illness effectively. One divorced woman with a young child living at home described her situation:

I've found it almost impossible to get on living a normal life with a family. I can't eat what she's eating anyway. I find it a strain. I generally skip a lot of meals. I haven't got the time or the energy. By 4 or 5:00 I'm ready to sleep. (7-6)

This woman was quite depressed after a recent brain haemorrhage. She clearly felt her conditions disrupted her life because she found it a struggle to keep up with daily tasks and managing her family. Living with several chronic conditions while managing a family herself resulted in discontinuous self-perceptions. She found it too difficult to reframe the meanings she assigned to daily activities to be able to normalize her illness in some way.

## Barriers

Many of the participants experienced barriers in managing multiple chronic conditions. Such barriers often included things like managing weight, exercise, diet, lack of information and/or conflicting advice from health care providers, and managing stress/depression. Most participants described the difficulty of maintaining a healthy weight and being able to exercise because their condition limited their activities. For example,

Some days your legs just give away. You turn around and you nearly collapse. My knee seems to be getting worse. And it seems to be putting pressure on my other leg. It's like I've walked 20 miles but I haven't. (5-2)

This man was very frustrated because he was gaining weight but unable to exercise. Added to this, he could not get the knee surgery he needed because his doctor wanted him to lose weight before he would perform the surgery. This was an endless cycle of barriers for him.

One remarkable woman with eight major chronic illnesses described how she managed everything fairly well (with ups and downs within her trajectory) but eventually when she was diagnosed with her latest condition she had enough. This suggests there may be a threshold for being able to cope.

I was doing really well and now I'm back to square one. It goes from bad to worse, from worse to better. Then it starts the cycle again. It's like your body said, 'Well, you've not tried this one. Have this one now.' I've never been angry. I've accepted everything but I was angry about this. (8-6)

This woman developed good coping skills, having dealt with illness from a young age. She was upset about her latest diagnosis of gout because it affected her ability to maintain normality and independence such as opening jars and lifting things out of the oven. One of her favourite activities was cooking and when she was unable to cook she felt depressed. She also could not have medication for the gout because it would have interacted with her many other medications.

These are examples of disrupting assumptions and behaviours, notions of self-concept, and ability to mobilize resources. Those who felt more disrupted by the diagnosis of a new illness appeared to encounter more barriers in managing health and had difficulty with everyday activities. It could be that their latest diagnosis had the most impact on their life and the added uncertainty caused their illness trajectory to be in limbo.

Several people with multiple chronic illnesses had discrepancies between current and past abilities and activities and seemed unable to reconcile these differences. Those who experienced barriers seemed to be

dwelling on who they used to be and could not move forward and focus on the changes they needed to make in their lives within the limitations of their illness.

### PRIORITIZING “MAIN” ILLNESS

The participants discussed in great detail how it was important to identify their “main” illness and to keep it as stable as possible. Prioritizing conditions helped patients to keep their symptoms under control, and return to an acceptable way of life within the limitations of their illness. This was an important stage for patients as it often helped to set the illness trajectory in the right course and to keep the momentum going.

Prioritizing the illness that caused patients the most concern helped them to minimize the disruption it had on their life. Even though many people had the same illnesses (such as diabetes, arthritis, and heart disease) one disease would often take a different priority over another, emphasizing the important role of social context. One man captured this best:

Prioritize your illness and say which one is going to disable you most. You have to take the priority of what is worse to treat. If you have a lot of problems and then depression I'd work on the depression first because that affects everything else. (8-1)

This patient was most concerned that depression would cause a downward spiral on the illness trajectory. Thus, he focused on keeping busy and remaining positive so that depression would be kept to a minimum allowing him to maintain his health.

Although patients often prioritized their most recent diagnosis at first, as they became more informed about their condition and more confident in managing it they re-evaluated their situation and prioritized mainly based on three key reasons: (1) the unpredictable nature of the disease; (2) conditions that could not be controlled by tablets; and (3) conditions that tended to set off other problems.

#### *1. The Unpredictable Nature of the Disease*

Although chronic illness is ridden with uncertainty a few participants prioritized one of their illnesses over the others because of its particularly unpredictable nature. This included people with diverticulitis, Parkinson's disease, one person with lung problems, and several people with heart disease. Even those who recently survived cancer said they had more concerns about other problems such as diabetes, arthritis, and heart disease because they could not be cured. One man explains the unpredictable nature of his illness and why it is the greatest concern to him:

My final issue is diverticulitis. In many ways that is the thing that makes the most impact on my life because of the unreliability of it. You make plans to do something to go somewhere and at the last minute you don't dare leave the house because you don't leave the loo. In itself it's not an important medical issue. It's the social problem more than anything else. You can't be relied upon. You can't rely upon yourself. So that has the biggest impact on my life. (4-3)

This man found it difficult to reframe the meaning he assigned to daily activities simply because he was uncertain how to modify his lifestyle to accommodate his condition.

Another man described how he was affected by the unpredictable nature of Parkinson's disease.

I have Parkinson's disease. It's progressive but that's the only thing I'm suffering from at the moment. The heart doesn't seem to bother me. The Parkinson's affects you in many different ways. You shake. My hands shake when I drive. I'm becoming stooped. I suffer from rigidity in the back. Sometimes the muscles in my leg become starved of oxygen and it's very painful and yet I can have other days when I'm perfect. (8-3)

This man said that it was often difficult to plan things because he did not know how he would be feeling from day to day. His daily activities and lifestyle could not be adjusted to effectively cope with his condition because of its uncertainty. Past coping skills that were once used for his heart condition (diet, exercise etc.) did not seem to apply in this situation.

Only a few people prioritized heart disease over their other illnesses giving uncertainty as a reason. For example, one man described the unpredictability of his angina:

The shortness of breath. It can come on at anytime. I can walk up and down a flight of stairs 50 times a day then 1 time it will just hit me out of nowhere and I'm puffing and panting at the top of the stairs for no reason whatsoever. (9-3)

For this man it was the feeling of being out of control that disrupted his biography. He found it difficult to plan his daily activities because he was unable to determine when the symptoms would come on and whether they would worsen over time or stabilize. His self concept was constantly in flux as he pondered questions of how long will these symptoms last?

There did not appear to be any consistent pattern amongst those who prioritized their illness because of its unpredictable nature and number of other conditions they had or the order in which they were diagnosed. Given the uncertainty and lack of control that most of these people experienced, they often encountered a disruption in their biography. Patients who prioritized unpredictable illnesses did so to minimize the dis-

ruption to their biography. The uncertainty associated with the unstable phase in the illness trajectory is not knowing whether the condition will continue to worsen or stabilize. Patients in this category often questioned what the future would be like and if it was even possible to get symptoms under control to live a “normal” life.

### *2. Cannot be Controlled by Tablets*

Related to the uncertainty/unpredictability reason given above, several people prioritized one of their illnesses over the others because it was the only one that could not be controlled by medication. This included several people with arthritis, knee, and back problems who felt that the pain was not adequately managed by medication. For instance,

It's the knee that's the most concerning because everything else is controlled by tablets. The knee is a problem because if I have one little slip I'm in plaster again for 6 weeks. (8–2)

I've had a mastectomy and I've had my gallbladder out. I think the arthritis is the worst and yet that's the one that can't be treated. (10–6)

Being unable to control the pain influenced the management of other conditions and the performance of normal everyday activities. People in this category found it particularly problematic to follow their doctor's advice of getting regular exercise and maintaining a healthy weight because of the pain they were in from their arthritis. This limited their ability to stabilize their conditions and in some ways worsened them as they gained weight, affecting other problems such as diabetes and heart conditions.

One person with diabetes also identified with this category because medication was not helping. For instance, one man who had heart disease for over 30 years claimed:

The diabetes is now worse than the heart problem. This is the greatest problem for me because the rest of it at the moment is being controlled by medication. Medication isn't helping the diabetes. (6–1)

This man was in biographical limbo; the uncertainty of his diabetes was causing him a great deal of distress, not only because the symptoms could not be controlled but because it could also have further implications for his heart and (potentially) other health problems. The uncertainty of being able to control an illness threw people's self-concept into disequilibrium as they contemplated how to cope with all of their conditions.

### *3. One Condition Sets Everything Else Off*

The most common reason for prioritizing an illness was because it set the rest of their problems off. For many people this included diabetes,

asthma, heart disease, chronic obstructive pulmonary disease, arthritis, and knee/back problems. One woman with eight chronic health problems described how her asthma seemed to set everything else off for her:

All the asthma attacks have put strain on my heart which caused the angina and my pulse rate. You need to keep your main illness stable, which to me is my lungs. I think I could cope with the other bits of illness a lot better. It's when my lungs go off that it sets off a vicious circle. My pulse starts racing. That makes you panic and feel more stressed out. (8–6)

For her it was important to minimize the disruption and keep all of her conditions stable. This woman was diagnosed with a rare form of asthma at a young age and had learned quickly how one illness can affect another. She was frequently in and out of the hospital (mainly for her breathing/asthma) and wanted to maintain stability by living within the constraints of all of her conditions. This was difficult: she could not exercise regularly to maintain her weight and general health because of her erratic pulse rate. Being sedentary, along with the side effects of certain medications led her to be overweight, creating further health problems. Her biography did not seem too disrupted but rather was one of “preparedness.” She said that she “always had a bag packed” for when she was not doing well and thought she might need to go to the hospital. Her chronic illness was embedded with uncertainty, which she dealt with quite well.

For others, diabetes was the key condition to keep an eye on because it often influenced many other problems.

My main problem is diabetes because the further effect of diabetes is not only the heart but eyes, feet, and kidneys. I had diabetes first, for about 20 years now. The first 8–10 years was controlled by diet and exercise. Diabetes is the main one for me because the diabetes is now affecting the kidneys. (9–2)

Although this man had anticipated many of his conditions, his biography seemed disrupted by the interacting effects by the uncertainty surrounding multiple problems.

Some people were concerned about putting on weight and the impact that this would have for their health because they were limited in the exercise that they could do.

My problem now is walking because of the arthritis in the knee. I can't put pressure on it. There are pieces still floating about inside it. That kills. The doctors tell me to exercise it. My problem is I'm getting fat because I can't do what I used to do. (10–1)

This man wanted to stabilize his conditions by maintaining his weight and staying fit but felt limited in the extent that he could do so. Indeed,

he and others were disappointed by the lack of information they received about how their conditions influenced one another. People often found it very difficult and frustrating to exercise when they were either fatigued from a particular condition or in constant pain. This often worsened their health because they tended to put on weight when not able to exercise.

Prioritizing an illness was often linked with conditions that had the greatest uncertainty. It was the feeling of being out of control and unpredictability that patients were most concerned with. The uncertainty of how long their conditions would continue to affect one another caused them great anxiety. Past experience with illness did not always help and often left them with disputed self-concepts because they could not normalize their illness and carry on a routine.

## DISCUSSION AND CONCLUSIONS

With the rising burden of chronic illnesses and increased emphasis on self-care it is important to develop a better understanding of how patients manage multiple chronic illnesses. This research addresses two important gaps in the literature. First, it explores how patients manage multiple chronic illnesses — past studies have focused on barriers encountered rather than the actual process — and how patients prioritize which illness to focus on. Second, little is known about how the concepts of “biographical disruption” and “illness trajectory” apply to people managing multiple chronic illnesses.

These findings suggest that biographical disruption and illness trajectory are shaped by social context and previous illness experience. Some people (especially those who were younger and those who encountered barriers in managing their health) were particularly disrupted with the diagnosis of a subsequent illness. Others did not seem as disrupted and were more accepting because of their age and/or because they had anticipated it. These findings are similar to others (Faircloth et al. 2004; Sanders et al. 2002) which suggest that people constructed their illness as a normal process of aging.

Most participants emphasized the importance of keeping their illnesses stable and maintaining a “normal” life within the limitations of their conditions. For many people with multiple chronic conditions illness was already a part of their biography (Pound et al. 1998) and did not necessarily disrupt assumptions and behaviours if they had already developed good coping skills or anticipated the onset of the illness. Those whose lives were disrupted by their illnesses were often younger, were caring for other family members, or encountered other barriers that influenced their ability to manage their conditions.

Patients older than 60 and/or those who were married seemed best at keeping their illnesses stable, possibly because they knew how to manage their condition. Their biography was maintained by staying positive, minimizing depression, and living as best they could within their limitations. This is similar to the research of Faircloth et al. (2004), who argued that instead of disrupting a biography an illness such as stroke can be integrated with other social factors to construct a biography that continues to flow across time. Indeed, the effects of having multiple chronic health problems are often normalized and placed in the pre-existing biographical context of the individual. As with Roberto et al.'s (2005) findings, this study found that those who were able to accept their illnesses and the limitations they imposed on their lives coped better than those who could not reconcile the changes or encountered barriers.

Bury's notion of "biographical disruption" is applicable to multiple chronic illnesses; however, it may not capture the range of experiences and the process involved in managing chronic illness. Some have argued that the concept of biographical disruption may be more complex than Bury suggests (Kelly and Field 1996; Williams 2000). The current experience of chronic illness may be less disruptive than in the past as a result of a wider range of explanatory models and a broader definition of normality (Richardson et al. 2006). Further, some argue that chronic illness may be "biographically anticipated" rather than disrupted, especially amongst those who have already lived hard lives such as the working class (Pound et al. 1998), which could be the case with this sample. Others have suggested that disrupted biographies can coexist with normal biographies (Sanders et al. 2002) and that an illness can have multiple trajectories depending on life circumstances (Reynolds 2004). This is where it has been useful to apply Corbin and Strauss' illness trajectory model.

The illness trajectory model took on a slightly different form and pace when applied to multiple chronic illnesses. A key difference from illness trajectory models that focus on one disease is that patients consistently described how they needed to prioritize their "main" illness to help stabilize their symptoms. Although the type of illness and the order in which they were diagnosed varied a great deal, it was vital to keep their main illness stable. Patients in this study prioritized their illness based on the unpredictable nature of the disease, the condition that could not be controlled by tablets, and/or the condition that set off other problems. Most patients worked hard to separate themselves from the disease and to normalize their condition within their current biography. These findings are consistent with Thorne et al. (2003) who found that patients want to control their disease rather than be controlled by it.

Patients played an active role in shaping the course of their illness. Having more than one chronic disease influenced response to illness and movement along the illness trajectory. Patients discussed how they moved between phases more often than they would had they only had one illness. The illness trajectory was shaped by actions of individuals and families to produce a stable disease course, fewer exacerbations, and better controlled symptoms (Corbin and Strauss 1991). It was evident that the natural course of illness trajectory was influenced by the interplay of social, economic, and physiological factors. Several patients encountered barriers (especially social, economic, and physical) that influenced their downward spiral towards the unstable phase where patients could no longer control their symptoms at home.

This was an exploratory study, limited to perceptions of illness and use of management strategies at one point in time. It adds to knowledge of the sociology of chronic illness by highlighting the complexities in changes to biography as patients manage multiple chronic conditions. Social context also plays a key role in shaping the illness trajectory. Further research should be directed in several areas. First, longitudinal research could capture how patients move from one stage to another over the course of the illness trajectory. Second, more insight is needed into the sociodemographic differences and the order of illnesses on prioritizing illness.

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