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Bodily changes among people living with physical impairments and chronic illnesses: biographical disruption or normal illness?

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Abstract

This article focuses on individuals who are growing old with chronic illnesses and early onset impairments. Their experience of illness complications, bodily and functional losses is similar to what Bury has referred to as a biographical disruption. However, whereas Bury argues that a chronic illness amounts to a critical situation for the individual, partly due to its unexpected nature, this does not apply to the participants in our two studies. A second difference concerns Bury’s implicit suggestion that the disruption is a single event that is characteristic of the early stage of a chronic illness. Repeated disruptions seemed to shape the lives of several of those interviewed. At the same time, this article challenges studies which suggest that the notion of disruption is less relevant to people in later life and to those who have experienced difficult lives, and also questions the argument that continuity rather than change characterises the lives of people who have had chronic conditions since their early years. In its approach, the article responds to Williams’ request for studies in the sociology of chronic illness that extend the predominant biographical focus on the middle years of life to both ends of the life course.

Keywords: early onset impairments, chronic illness, biographical disruption, transitional process, normal illness

Introduction

The point of departure for this article is a recurring theme that has emerged in interviews with women and men for whom a chronic illness or injury had always been, or since childhood, adolescence or younger adulthood, has been part of their biography. The theme in question has to do with the upsetting, frightening or painful complications and bodily and functional losses that are experienced as part of their process of continued illness or physical deterioration. The aim of the article is to examine and discuss this experience and the meaning of these bodily and functional losses for the participants relative to the concept of
biographical disruption, as described by Bury (1982, 1991) on the one hand, and to the literature on normal illness (Williams 2000) on the other hand.

The article draws on two separate qualitative studies, one prospective and the other retrospective which, from a life course perspective, explored the experience of people living and ageing with various chronic illnesses and disabilities. Our analysis indicated that the participants’ experience of illness complications and functional losses was similar to what Bury (1982) referred to as a biographical disruption. However, whereas Bury argues that a chronic illness amounts to a critical situation for the individual partly due to its unexpected nature, this cannot be applied to the participants in our two studies; nor can the implicit suggestion that the disruption is a single event characteristic of the early stage of a chronic illness. Based on patterns in our analysis, we argue that the concept of biographical disruption may be used to understand a wider and more complex set of experiences in connection with repeated transitions due to bodily and functional losses over the life span in chronically ill and disabled people – losses that may have been both unexpected, feared and expected at the same time.

The article also questions the argument that conditions that one has had from early childhood should be regarded as normal for the individual, rather than disruptive, and that continuity rather than change characterises the lives of people who have had chronic conditions since their early years (see Williams 2000). The accounts of those interviewed who were born with or have had a chronic condition from childhood clearly illustrate how their lives, physically and existentially speaking, seemed shifting, disruptive and discontinuous, to various degrees, rather than continuous in the sense that Williams has suggested when speaking about normal illness (2000: 49–50). Furthermore, the article challenges the literature that supports the idea of normal illness, suggesting that the concept of biographical disruption is less relevant to older people and to those who have experienced difficult lives. We found hardly any support for the notion that bodily changes in later life or after many years with a disability are experienced as less painful or less disruptive than at an earlier age or closer to the onset of chronic illness or an impairment. Instead, we argue that the risk of experiencing a complication or bodily or functional loss as disruptive in some respects might be even greater after many years of living with a chronic condition than it would be earlier in the process.
Missing voices

People who have lived all or most all of their lives with physical impairments and chronic illnesses are still considered ‘missing voices’ (Lawton 2003: 36) in the debate on biographical disruption and in the sociology of chronic illness. Additionally, and consequently, a question that has remained largely unexplored is how individuals experience bodily changes and the loss of functional capacity that occur over the life course, years after the initial onset of a chronic illness, injury or congenital impairment. This is despite the fact that Bury himself, as well as scholars using the concept of biographical disruption, are aware that ‘the conditions that underpin most forms of disablement involve fluctuating symptoms’ (Bury 1982: 168) and that people may have to cope with progressive deterioration and recurring losses during their life.

In the sociology of health and illness, the important works of Charmaz (1983, 1987, 1995), focusing on how chronically ill people live through crises and complications as the years pass by, are notable exceptions to the focus on the onset of an illness in much biographically oriented research. In the field of disability research a few scholars (for example, Zarb and Oliver 1993) have touched on the experiences of already disabled people of losses of bodily function over the life course. However, in none of these works were the experiences in question thoroughly compared and discussed in relation to Bury’s concept – or the discussion that has followed the introduction of the concept. Additionally, apart from Charmaz, who followed some of her interviewees for approximately 5–10 years, none of these previous works includes prospective data.

Biographical disruption and normal illness: a background

Bury’s (1982) frequently cited article, ‘Chronic illness as biographical disruption’ has been widely recognised as constituting a significant contribution to our understanding and conceptualisation of lay experiences of illness (Lawton 2003). In his article, drawing upon interviews with individuals who had recently suffered the onset of rheumatoid arthritis and building on Giddens’ (1979) notion of a critical situation, Bury develops an approach in which the development of a chronic illness is viewed as constituting a major disruptive experience; a biographical disruption:

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which
underpin them are disrupted. Chronic illness involves recognition of the worlds of pain and suffering, possibly even of death, which are normally seen as distant possibilities or the plight of others. . . . Further, the expectations and plans that individuals hold for the future have to be re-examined. Thus, I want to maintain that the development of a chronic illness like rheumatoid arthritis is most usefully regarded as a ‘critical situation’, a form of biographical disruption. (Bury 1982: 169, our italics)

Since the publication of Bury’s (1982) seminal article, the concept of biographical disruption has been the subject of continuing debate. Bury (1988, 1991) has also developed his approach by stressing the importance of the practical consequences that illness has for individuals and their families and by more explicitly showing how the individual is an actor who actively handles and adapts to the change.

Normal illness

Several articles critically reappraising Bury’s concept have explored the possibility that chronic illness may be accepted as biographically anticipated ‘normal illness’ or ‘normal crises’ by the individual (Williams 2000) and, thus, not necessarily disruptive. The idea of some scholars is that in a context where hardship, traumatic events and problems of different kinds are considered to be more or less normal or are already part of the individual’s daily life and biography, the impact of a chronic illness may have less significance than the concept of biographical disruption might imply. For example, studies of illness experiences in older age (Charles and Walters 1998, Pound et al. 1998; Sanders et al. 2002) have developed the argument that a chronic illness might ‘cease to be ‘out of place’ or ‘special’ in old age’ (Priestley 2006: 86) and, thus, may be experienced as more expected and less disruptive. Expressions such as ‘biographical continuity’ (Williams 2000: 52), ‘biographical flow’ (Faircloth et al. 2004: 356) and ‘biographical confirmation’ (Williams 2000: 50) have been introduced to conceptualise this phenomenon.

There is another, somewhat different, life course dimension that, besides age and general living conditions and expectations, has received attention in the debate, and which critically reappraises the notion of illness as a biographically disruptive event. This concerns the argument that, for some people, a chronic condition experienced from birth or childhood may be part of normal everyday life and thus may not necessarily be shattering or disruptive. In his important review of the literature on biographical disruption Williams (2000) argues that the concept of biographical disruption, like much biographically oriented research on illness, is
predicated in large part on an adult-centred model of illness denoting the shift from a normal state of health to one of illness (p. 49). One of the consequences of this largely unquestioned assumption brought forward by Williams – without reference to empirical research – is that

the whole question of conditions which one has from birth or early childhood, including congenital abnormalities and deformities, is neglected: conditions, from the very start of life, which are integral to an individual’s biographically embodied sense of self. . . . The lives of these individuals may appear (profoundly) disrupted. Yet, phenomenologically and existentially speaking, it remains the case that these biographies have not, in any real or significant sense, shifted. Continuity rather than change remains the guiding principle here, including important elements of biographical confirmation or reinforcement. (2000: 49–50, italics in original)

Concerning future agendas, Williams underlines the need for an extension of the biographical focus of studies in the sociology of chronic illness ‘to both ends of the life course, thereby moving away from the hitherto predominant concern simply with the middle years of life’ (p. 61, italics in original). ‘Greater attention to the timing, context and circumstances within which illnesses are ‘normalised’ or ‘problematised’ and the manner in which identities are threatened or affirmed’ (p. 62, italics in original) is also called for. The latter is underlined by Wilson (2007) in her more recent contribution to the debate on biographical disruption and normal illness. This article aims to respond to these requests by Williams and Wilson.

Method and materials

The article is based on the analysis and comparisons of results from two qualitative studies in which a life course perspective (Giele and Elder 1998, Plummer 2001) was used as a methodological orientation. Peoples’ descriptions of their lives were viewed as a way to grasp a sense of their experience of living with illness and disability over a long period of time and during different phases of life. In both studies, data were collected through semi-structured interviews that were recorded and then transcribed verbatim. This work was carried out in close adherence to ethical principles, as was the rest of the research process in both studies.¹

The first study (the prospective study) is a study of chronically ill, visually impaired people who were repeatedly interviewed over 30 years. The overall purpose of the interviews was to understand the lives and life changes of people who live for many years with chronic illness and severe disability, as well as what situations had been of formative importance for the
biographies of the studied group. Data were collected through interviews that were repeated five times after the first round of interviews in 1981. Further interviews were conducted in 1985, 1988/89, 1999, 2006 and 2011. The participants consisted of five women and nine men – 14 people (at baseline), aged 30–45 at the time of the first interview. All of them had acquired severe visual impairment as a first major disability due to chronic illness. In 11 of the cases, this illness was juvenile diabetes. At the beginning of the 1980s diabetes was the major cause of acquired visual impairment and blindness among younger adults in many western countries (Turk and Speers 1983). Three people had a visual impairment due to a congenital eye disease. The first interview took place 1–2 years after the onset of visual impairment, at which time eight of the individuals interviewed were already totally blind. When the last round of interviews was conducted in 2011, 10 out of the 14 participants were still alive. At this time, among those for whom the primary cause of visual impairment had been diabetes, all had various illness complications to the primary chronic illness that had affected them over the years. The analysis of data was mainly conducted as a qualitative, comparative content analysis with focus both on present conditions, on retrospective comparisons and on deliberations about the future. This way, patterns of change over the life course could be identified (Jeppsson Grassman 1986, 1991, 2001, 2008).

The second study (the retrospective study) had a retrospective design and was conducted with the overarching aim of investigating the implications of social and chronological ageing for people aged around 65 who had lived with a physical impairment for many years (Taghizadeh Larsson 2009). In all 20 people – 11 women and nine men between 56 and 72 years of age at the time of the interview in 2005–2006 were chosen to participate in the study. The period during which the participants had lived with disabilities ranged from 30 to 66 years. Seven had lived with a chronic condition since birth or since they had been less than 1-year old. The diagnoses reported were the following: polio (six), multiple sclerosis (MS) (six participants had at one time been diagnosed with MS but four of these had uncertain or ambiguous diagnoses), cerebral palsy (three), spinal injuries (two) and stomach and intestinal diseases (two). Two respondents reported other, more uncommon diagnoses and one reported two different diagnoses. In all 19 of the interviewees were dependent upon some form of mobility support more or less all the time; 15 primarily used a wheelchair. The analysis of the material in this study was carried out following the procedures of a directed approach to content analysis (Hsieh and Shannon 2005). Thus, previous theoretical discussions and findings on social and chronological ageing and the implications of ageing for people living
with impairments guided the formulation of the research aims and were used in the analytical process. The analysis can also be described as abductive (Mason 2002).

The discussion in this article is based on a third analytical phase in which the results of the two studies were compared. Here, one focus was on a certain theme that had been uncovered independently in both studies and that was associated with illness complications and bodily changes and the feelings that the interviewees attached to these.

While the two different research designs used in the studies share the aim of capturing ‘a “movie” rather than a ‘snapshot’ (Berthoud 2000: 15) of social life, results from such studies tend to differ in ways that suggest that prospective data are more appropriate than retrospective data to address certain research questions (see for example, Cohen et al. 2005). Apart from being less appropriate when detailed information is required, comparisons have also shown a tendency in retrospective studies for past difficulties to be underreported in comparison to more recent problems. In accordance with these findings, the interviews from the retrospective study comprised vivid accounts of upsetting and painful experiences of recent losses of bodily capacity, while losses that had occurred earlier in life were mentioned only in passing. Without the prospective data, where we could see that similar accounts of recent changes were repeatedly given by the same interviewee at different points in their life course, it might have made sense to understand these accounts and experiences as ‘ageing-related’, as other scholars working with retrospective data have done (for example, Pentland et al. 2002). However, the retrospective study also contributes to our argument in this article, not because of its retrospective character but because it included several individuals with ‘conditions which one has from birth or early childhood, including congenital abnormalities and deformities’. These are individuals in the specific category that Williams (2000: 49–50) explicitly refers to in his argument that some people’s lives, despite impairments, are better defined as continuous than disrupted.

In the next sections we examine and discuss the experience and meaning of illness complications and of bodily and functional losses for the participants in the two studies, relative to the concept of biographical disruption as described by Bury (1982). We also contribute to the discussion on whether the lives of those who have had chronic conditions since childhood are to be viewed as continuous, rather than disrupted. Furthermore, based on our analysis, we demonstrate how ageing and living a long time with a disability, shaped by hardship in terms of repeated episodes of bodily deterioration, do not necessarily make complications and bodily and functional losses easier to handle in the way suggested by, for example, Carricaburu and Pierret (1995), Charles and Walters (1998), Pound et al. (1998) and
Recurring complications and bodily losses with various meanings

Firstly, it is worth emphasising that, in spite of the wide range of diagnoses included, all of the participants in the two studies gave accounts of recurring illness complications or bodily losses. The interviews conveyed a picture in which chronic illness and disablement appeared as parts of a transitional process that, for some participants, had been going on since birth or early childhood. For others the process had started in adolescence or in younger adulthood. There was no once and for all level of health or functioning. In many cases, the disabling conditions were caused by chronic illness where there was a continued risk of complications to the primary illness. This was particularly striking in results from the prospective study in which such patterns of change over 30 years were identified:

Karin, for example, was visually impaired due to diabetes since childhood. She was 40 when first interviewed in 1981. Then, she was already seriously visually impaired due to gradual loss of eyesight. After that, she had been afflicted with various illness complications. At the time of the interview in 2006 she gave an account of what had happened since we had last met (in 1999). Surgery on her hands and feet had been necessary and she had had by-pass operations on her legs due to poor blood circulation. En passant, she also mentioned that, a couple of years earlier, she had broken a femur and a shoulder after a fall caused by an insulin coma. The follow-up in 2011 indicated that since we last met she had also had some heart surgery.

Despite the broad range of disabilities covered in the retrospective study, several of those interviewed had had similar trajectories, characterised by continued bodily deterioration. For some of them, this theme seemed to dominate their deliberations and comparisons regarding life with a disability in different phases of life. Ingrid (68-years old), who has cerebral palsy, is an illustration: she described her childhood as shaped by repeated stays in hospitals and by surgery. Her late adolescence was, she says, her best phase in life: ‘Then I was in better shape than I have ever been before or since’. Later in the same interview, when Ingrid was asked whether she experienced any difference between living with disability at the age of 68
compared to 48 she answered: ‘In my case, the situation is this: at 48 I was in an incredibly much better shape than I am today, at 68.’

The complications and losses were experienced in various ways. While some were described as quite harmless by the participants, others were associated with feelings of pain, worry and fear. In some cases, very similar losses appeared to be rather unproblematic to one individual but as very problematic or critical to another. However, what several of the critical complications or losses seemed to have in common was that they entailed fears of becoming more dependent on other people, or having to leave work or give up other activities important to the individual. Often, these changes appeared to have particular existential meanings for the individual by being connected to privacy and access to moments ‘back stage’ (Goffman 1990), where one could relax from the roles played in front of other people, or to uncertainty regarding one’s future and identity.

Privacy and threatened moments back stage

A central theme in many interviews was a lack of privacy in the daily lives of the participants. ‘To be forced to have strangers around for help all the time gives you no chance to live a normal life’, said Birgitta (55-years old in 2006) bursting into tears when she pondered her 25 years with blindness. This was a constant problem. However, there was a limit when the lack of privacy due to complications and losses became too painful, since it threatened the individual’s integrity and their last chances for cherished moments back stage. An illustration of this in the retrospective study is Inger (67 years old, with polio since childhood) and her account of a recent, temporary paralysis of one of her arms.

Inger had been using a wheelchair since she was in her twenties. At the time of the interview her personal assistants supported her with daily tasks for several hours every day. However, she could still manage the intimate and frequent task of going to the toilet, as well as getting herself to bed at night, without help. It was evident that she greatly valued being able to do these things alone without the presence of assistants. The paralysis seemed to imply a fear of becoming more dependent on assistance than she already was, and for very private things:

I almost feel that when your arms, when it starts with your arms then it’s a disaster, I think. Because I am totally dependent on my arms to take care of myself and if they collapse then I have to have help around the clock. So it’s, it felt like a catastrophe when I became paralysed in the arm. Oh, that is, ugh. . . . not to be able to go to bed by myself, not to be
able to handle going to the toilet. That is the worst . . . I don’t want someone running here all the time to help me.

An uncertain future

The fear of new illness complications and bodily losses was brought up by many of those interviewed – in the prospective study repeatedly over the years – and in the retrospective study by most interviewees. In several cases, it was obvious that this fear of new losses was connected with strong feelings of uncertainty regarding the future which had existential implications:

Sometimes I feel like . . . maybe it would be easier if things were final . . . now I have this all the time, all the time . . . I don’t know what it will be like tomorrow, perhaps it will be worse. (Lars, 50 years old, in 1989)

For several of those interviewed in the prospective study, most of whom had suffered from serious complications to their diabetes, a variety of possible further complications such as a heart attack and kidney failure – or complications in general – took on specific existential meanings since they tended to arouse an awareness of death and a fear of loss of life:

The complications . . . not knowing how fast they will proceed . . . how many years I have left. Each time I have a new health problem I wonder: how much longer? (Erik 62 years old, in 2006)

This sort of anguish was the companion of many of those interviewed through life, regardless of age and time since onset of illness and disability.

Threatened identities

A range of apparently critical complications and bodily and functional losses did not only entail loss of work opportunities and other valued activities. The possibility of asserting a cherished self-image or social identity (Jenkins 2003) also diminished, as did the chance of having that identity confirmed by others. One example is the painful experience of Lars (the prospective study), who had had to have one leg amputated.

Lars was 50 when interviewed for the third time, in 1989. Through the years the interviewer had followed him in his struggle to keep working, in spite of total blindness due to diabetes, in a craft that was very important to him. When he had to have one of his legs amputated this was no longer possible: ‘My world fell apart’, Lars said. ‘I felt like I had nothing left . . . what would become of me?’
Strong resentment about a functional loss that resulted in the need for a wheelchair was a theme that featured in some of the interviews. In a number of cases, this might be understood as being connected to the common image of a disabled person as a wheelchair user, and the individual believing her chance of being seen by others as normal and non disabled as lost by the need for this aid. The story of Eva (aged 65), in the retrospective study, is one example of this. Eva was born with a limb deficiency which meant that she came to walk, as she said, in a ‘very special way’. It was not until she was in her teens that she got the diagnosis - cerebral palsy. The leg fracture eight years earlier was not her first one. She had broken the same leg twice before. However, it was this apparently critical fracture that made it necessary for her to start using a wheelchair:

It was a disastrous day. ’97, it was. And you know, it was my best leg that I broke. So, unfortunately. . . . But one has to try to survive. You say that you don’t want to live. But that’s no use saying when everyone else around you says, ‘Of course, you have to live on’. What for? This is no life, to sit in a wheelchair.

Several times during the interview Eva said that since early in life she had struggled to belong to ‘the ordinary – non disabled – people’. She said, ‘I have always tried to be with the healthy ones’, ‘I have always taken pride in being an ordinary Mrs Larsson’. Thus, although some people might consider Eva as a person who has been disabled from birth, she herself seemed to have been resisting this identity as a disabled person for most of her life, striving for others to see her as at least almost healthy, normal and non disabled. This adds to the understanding of why the fractured best leg, which resulted in a need for a wheelchair and in a sense turned Eva into a ‘typical disabled person’, made her wonder if life was still worth living.

**Cases of biographical disruption?**

Concepts such as a ‘critical situation’ and ‘biographical disruption’ undoubtedly seem appropriate to describe the experience of the complications and bodily and functional losses – charged with emotions of pain, worry and fear – that the participants in the two studies described. Additionally, the meaning that several of these bodily changes seemed to have for the individuals corresponds rather well to Bury’s description of a biographical disruption as involving ‘re-thinking of the person’s biography and self-concept’ (Bury 1982: 169) as well as to his (1982: 169) argument that increasing dependence is a major issue relative to a biographical disruption. However, in some respects, Bury’s description of a biographical
disruption is too narrow to capture the complex set of experiences expressed by our participants.

The ambiguity of unexpected and expected disruptions

Central to Bury’s definition (1982) is that it bears upon an unexpected event that disrupts an expected life course that has been taken for granted. The critical complications and losses experienced by the people interviewed in our two studies rather had the character of feared disruptions which ended a hoped-for life course. The results of our analysis give no reason to believe that these lived bodily changes drew the attention of those interviewed to ‘the worlds of pain and suffering, possibly even of death, which are normally seen as distant possibilities or the plight of others’ (Bury, 1982: 169). They knew that this plight could very well be theirs.

On the other hand, in a certain sense, expected events may be unexpected. This was the experience of Björn (40 years old, congenital eye disease) in the prospective study:

I have lived all my life knowing that I might lose my eyesight . . . from the beginning. It was in the family. I focused my life planning on it. Yet when it happened, I lost my grip on life. I did not know what to do with myself or how to go on.

While that which is expected has to do with the insight that illness complications or functional losses are likely to occur eventually, the unexpected aspect is that it is happening now. The participants seemed to live with double timetables or ‘body tables’, where complications and losses were both expected and unexpected events. Thus, in a sense, these bodily changes seemed to both confirm and disrupt the individuals’ biographies. Because of their insight into the probable progression and prognosis of their illness, most of the interviewees seemed to be well aware of what could happen. At the same time, in order to have a tolerable life, they had to live as if what could happen would not happen, not to them, or at least not just now. At the time of the first interview in 1981 Christine (aged 40), who had previously lost all eyesight, had just had some surgery that had given her back a little sight in one eye. Through the years this had been very helpful for her, and 25 years later she tells the interviewer:

I can never be sure. I am still doing my little check-up in front of the mirror, first thing in the morning, to make sure I have my little eyesight. And each day I think, now I am safe one more day.

When interviewed again in 2011 she confesses that she still uses her ‘little check-up routine’.

Recurring disruptions
A second difference concerns Bury’s suggestion that the biographical disruption is an event characteristic of the early stage of a chronic illness. The two studies conducted, as well as other studies on people who have lived with a chronic condition for a long time (for example, Charmaz 1995, Zarb and Oliver 1993, Pentland et al. 2002), illustrate that the types of experiences, fears and threats in question may emerge as recurring elements in a life with physical impairment and chronic illness, and not only as a single event in connection with the onset of the illness or the first disabling condition. The 30-year perspective that the prospective study enabled suggested that the people interviewed repeatedly tried to adapt – normal is – at new levels of health and functioning, only to have to experience disruptions of the acquired new normality (cf. Locock et al. 2009) due to illness complications. In spite of his blindness and diabetes, Krister (aged 55, in the prospective study) had, for many years, kept up active volunteer roles, in politics, in the disability movements, and so on. until a few years prior to the interview in 2006. Now, too ill and too disabled after a kidney failure and several heart attacks, he spent most of his time at home. ‘Now I am nothing,’ he said. ‘That has been somewhat of a crisis’.

Cases of normal illness?

Discontinuous lives with chronic conditions since childhood

Several of those interviewed in our retrospective study were born with, or had lived with, a chronic condition from early childhood. Yet, as their stories (Inger and Eva cited earlier for instance) clearly illustrate, bodily losses seemed just as critical and disruptive to them as to the other participants. In the light of their accounts of bodily changes over the years, their lives, physically and existentially speaking, seemed shifting, disruptive and discontinuous to various degrees, rather than continuous, in the sense that Williams has suggested when speaking about normal illness (2000: 49–50). To put it differently, one might also say that what appears as continuous in these participants’ lives is that they were repeatedly confronted with more or less critical bodily changes.

Non-disruptive losses

As already mentioned, not all bodily losses seemed to be experienced as critical or disruptive by the participants in the two studies. In accordance with the idea of normal illness (Williams 2000) one might think that the reason for this would be that individuals who have multiple illnesses and are disabled ‘get used to this’ or ‘become toughened’ in the end, and with time, find it easier to handle new functional losses or complications to their primary illness. One
might also think that, having reached an age when impairments are considered to be more ‘on time’ (Neugarten and Hagestad 1976), according to age norms, new losses would be less upsetting (cf. Charles and Walters 1998, Pound et al. 1998, Sanders et al. 2002). However, we did not find support for these patterns in our studies. Rather, what the ‘unproblematic’ changes in our data had in common was first and foremost that they did not seem to have a particular existential meaning for the affected individuals by threatening their privacy or a cherished social identity. Nor did they seem to be connected with feelings of uncertainty regarding the future. Examples of non-problematic losses were, for example, the amputation of both legs and a complete loss of leg function cited by participants in the retrospective study, the common denominator being that they had lost their ability to walk much earlier. One example is Åke – 65 years old and diagnosed with cerebral palsy:

I was not sad because they had taken my legs . . . because I could not walk on my legs anyway. And I said that. My cousin, he thought it was so strange.

The difference is striking between Åke’s account of the amputation as something that did not really affect him, not even at the time of amputation, and Lars’s and Eva’s accounts of similar – but apparently critical – losses. However, as Åke had already needed a wheelchair for several years at the time of the amputation, one might perhaps say that the amputation – unlike Eva’s leg fracture – confirmed his social identity as disabled. Furthermore, unlike in the case of Lars, the amputation did not impact on Åke’s daily life activities. Nor did the amputation seem to have aroused in him the awareness of death and fear of loss of life that many complications seemed to generate for the participants in the prospective study, most of whom had diabetes. This, in turn, might have to do with the different nature of the diagnosis, personality and other circumstances, such as the kind of information available about the causes and consequences of the amputation.

The significance of age and timing

Mediating factors such as age, having lived with a chronic condition for a long time, or general hardship, all of which have been given attention in articles that adhere to the idea of normal illness, do not add much to the understanding of the participants’ experiences of complications and losses. In our interviews with people with a variety of chronic conditions, we found hardly any support for the argument that ageing or time spent with a chronic condition and recurring bodily changes would make it easier to confront new complications or
losses. Rather, it seemed that the risk of experiencing a complication or a bodily or functional loss as critical or disruptive might be even greater after many years of living with a chronic condition than earlier in the process. As in the cases of Lars, Krister and Eva cited earlier, and for several of the other participants, critical bodily changes seemed to occur at a relatively old age and after many years with disabilities, recurring complications and losses. In this context, a further loss became a kind of straw that broke the camel’s back and that forced them to finally give up a job, valued activities or a social identity that they had been striving to keep up for many years.

Yet, at the same time and in the very long-term perspective, our analysis indicated that the mere experience of having surmounted repeated disruptive illness complications and survived them might for some, with age, and time, inspire some confidence regarding one´s future ability to handle new complications. This pattern became visible when the focus in the prospective study was turned towards the phases of relative stability between episodes of complications and towards the strategies that were used by the participants. Krister’s narratives over the years illustrate this: recurring bodily losses, disruptions, threatened identity and the uncertain future, but also, at the end, new confidence about his ability to handle complications in the future.

Krister was 30 years old when interviewed for the first time in 1981. He had become blind a couple of years earlier as a complication of diabetes. He was glowing with enthusiasm. The blindness had changed his life completely, but mainly in a positive sense, he maintained. It had made him break away from his small-town life, he said, and he was looking forward to new education. When interviewed in 1985 and in 1989 his situation was different: he was suffering from high blood pressure and beginning neuropathy and he had had to give up a cherished job because of this. His world-view was now coloured by these complications and their possible consequences: ‘It is like a door that has been opened’, he said. ‘You can never forget what is behind that opened door once you have seen it’.

Krister was interviewed again in 1999 His trajectory was shaped by illness complications and losses. He had been trying to make something out of his life, yet each time he was stopped by illness and new loss of functioning. Each time it was just as painful. The first loss did not seem to be the worst one. When interviewed in 2006, he said:

Before, it was all about my visual impairment . . . but so much has happened in these last few years: kidney failure last year, and heart failure, my fifth heart attack. I try to think rationally about it, but it is not easy . . . I get so upset and worried somehow.
When interviewed again in 2011, he was 60 and another five years had passed. He had had new complications. Yet, somehow he seemed a bit more confident: ‘I have been through so much’, he said. ‘I don’t know . . . but perhaps I am better at handling things’.

**Conclusion**

Responding to Williams’ (2000) request for an extension of the biographical focus of studies in the sociology of chronic illness ‘to both ends of the life course’ (p. 61, italics in original), the point of departure for this article was a recurring theme that emerged in interviews with women and men for whom a chronic illness or injury had always been, or since childhood, adolescence or younger adulthood, had been a part of their biography. The theme in question is the upsetting, frightening or painful complications and bodily and functional losses that were experienced as part of their process of continued illness or physical deterioration.

In this concluding section, we would like to stress the theoretical implications of the analysis presented in this article. Firstly, we would like to suggest that the substantive reach and potential of the concept of biographical disruption is wider than the Buryan tradition implies. In this tradition it mainly functions as a conceptualisation of how previously healthy individuals may experience an unexpected onset of a chronic illness in a situation where that is the first major loss of bodily and functional capacity that they have been confronted with. Based on the accounts and experiences of those interviewed in our studies, who were people who had lived for many years with illnesses and impairments, we argue that biographical disruptions may occur repeatedly over the life span in chronically ill and disabled people, and that illness changes do not necessarily have to be wholly unexpected to be experienced as disruptive. In our view, the concept of biographical disruption, redefined, may also be used to understand a wider and more complex set of experience in connection with repeated transitions due to bodily and functional losses over the life span in chronically ill and disabled people. These losses may have been unexpected, feared and expected at the same time, and may have disrupted a wished-for scenario for the future. Our data, which were collected over 30 years, have allowed for the substantiation of these patterns in a unique way.

Secondly, we take a critical stance towards the argument of ‘normal illness’. We have drawn attention to the fact that neither old age nor a long life with disability shaped by repeated illness episodes necessarily seem to make bodily and functional losses less disruptive. We have also challenged Williams’ (2000) suggestion that conditions that one has from early life should be regarded as normal for the individual, rather than disruptive. The
accounts of bodily losses that have been presented clearly illustrate how the lives of those interviewed seem shifting, disruptive and discontinuous rather than continuous, in the sense that Williams argued (2000: 49–50). We would like to suggest that a problem with the concept of ‘normal illness’ is the built-in assumption that illnesses and impairments are either experienced as unexpected, disruptive and critical or as biographically anticipated and thus quite unproblematic for the individual. Several of the complications and losses that the participants in our two studies told us about might very well be described as critical and as biographical disruptions and as dimensions of expected normal illnesses at the same time. Our conclusion is that, in order to assess the accuracy and substantive reach of the concepts of normal illness and biographical disruption there is a need for more refined contextualisation. The analysis presented in this article contributes to such work.

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Notes

1 A specific ethics clearance certificate was not required for the studies at the time they were initiated. The funding bodies required adherence to common ethical principles. In both studies, the following principles were adopted and complied with throughout the research process: (i) the principle of right to information, (ii) the principle of informed and voluntary consent (with the right for the individual to end participation at any time) and (iii) the principle of confidentiality. In the prospective study these principles had particular significance and were followed with great care over the years.

2 In the empirical quotations from this study, the age of the interviewees mentioned is their age at the time of the interview, unless otherwise stated.

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