

Disability and identity across the life course

The restricted growth experience

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This paper seeks to examine some aspects of disability identity in the light of a recent research project which focused on medical, health and social dimensions of life as an adult with a skeletal dysplasia, a range of conditions causing restricted growth or dwarfism. We question the significance of a simple classification of people with impairments as 'disabled' by highlighting the discrepancies found in the extent to which respondents in the study identified themselves as disabled, and the difficulties many found in recognising themselves as 'different'. In particular, we argue that disability identity should be understood as dynamic and changing over the life course, and suggest that major transition periods can act as crucial focal points when there may be a re-assessment of identity as 'disabled' or 'different'. Overall, we evaluate disability identity in terms of the relationship between experiences of impairment – symptoms such as pain, numbness and reduced mobility – and experiences of affiliation – focusing on quality of life, barriers to inclusion and the attitudes of others. In so doing, we reveal the tensions between the drive to integrate and be considered on equal terms with the average-sized population, and more negative experiences of exclusion and dependency.

[disability, ageing, life course, restricted growth, transition]

Introduction

This paper explores the experience and social identity of people with restricted growth, particularly as that changes over the life course. Based on the qualitative findings from a mixed methods research project in Northern England, the aim is to show that disability identity is more dynamic than materialist disability studies authors often allow for, and to reiterate the importance of health symptoms, albeit within the overall social context.

Disability is a complex concept. It can be defined strictly biologically, as having a particular impairment, or experiencing a particular functional limitation. While apparently simple, such approaches often have to specify a threshold, at which variation becomes defined as disability (Bickenbach et al. 1999). Another approach looks at

disability as an administrative category (Stone 1985), relating the definition to the requirements of a social security bureaucracy. Culturally, it is clear that the notion of disability relates to particular stereotypes and representations, for example as “other” (Shakespeare 1994). In particular social contexts, disability may be defined or regarded in different ways, with implications for the ways in which individuals see themselves. Medical sociology approaches have emphasized the way that illness transforms the self, focusing on the subjective dimension. Hence concepts such as “spoiled identity” (Goffman 1968) or “biographical disruption” (Bury 1982).

However, the materialist tradition in British disability studies has tended to conceive of identity in political, rather than psychological or social terms, against the backdrop of a redefinition of disability as structural and social, rather than individual and medical (Oliver 1990). In this account, disability identity arises from the experience of oppression and social exclusion. Disabled people come together in the context of self-organised disabled people’s organisations, direct action and disability arts activities to share common experiences and transform a negative and medicalised experience into a collective identity based on solidarity, pride and resistance (Swain and French 2008). For Oliver (2009), identity is a three-fold phenomenon: having an impairment, experiencing oppressive barriers, and identifying with the disability movement. Yet the “common sense” understanding of disability remains based on the notion of impairment, the so-called “medical model”.

While disability as a category or as an identity can be conceptualized in different ways, the phenomenology of disability is more complex still. Identities can be chosen, not simply given. The rise of disability as a viable and positive political identity has changed the possibilities for individuals with disabilities, who can now decide to self-define in a particular way (Hacking 1986). Some people with impairments deny their differences; others identify in terms of their medical condition; others opt for political affiliation; others may find disability less salient than their other attributes (Shakespeare 2006). Watson (2002) found that many in his study who had what could be considered serious impairments failed to recognise themselves as disabled. The ‘disabled’ identity was either one which they did not consider applied to them, or for certain reasons they deliberately rejected the identity. He supports an approach that sees disability as only one of multiple identities open to individuals, based on gender, ethnicity, sexuality, family role, etc., and which coexist and are subject to prioritisation, and he sees little evidence of restrictions on the individual’s freedom to choose. In fact, he challenges the importance of oppression as a factor in this choice, and suggests that those who reject a disabled identity are expressing their view that their impairment is unimportant and a source, quite simply, of ‘difference’ which (despite the acknowledged existence of barriers) does not set them apart from what they term ‘normal’ people. The implication of these new approaches is that disability identity should not be regarded as a homogenous concept. It is intrinsically multi-dimensional, offering people with impairments different options for identifying themselves, albeit within the constraints of a disabling society.

One aspect of the diversity of the disability experience – and hence also of identity – is the particular point in the life course at which someone becomes disabled.

Those born with an impairment typically accommodate to their difference more easily than those who become disabled through injury or illness in mid life. Those who become impaired as a result of the ageing process appear less likely to identify as disabled, as opposed to just “normally old”. Some disabled children grow up to be non-disabled, just as some adults are disabled for temporary periods. However, it is interesting to note that many people who are born with congenital impairments, or who develop impairments early in life, may experience worsening of their condition or development of secondary conditions during the ageing process. Thus the distinction between “congenital” and “acquired” begins to break down, as congenital conditions can have acquired complications which may imply a changed sense of self.

Recent work has begun to explore disability across the life course (Priestley 2003). However, while highlighting the different issues confronting disabled people at different life stages, there has been little analysis of how identity may change through the life-cycle. The life course in western societies is embedded in a tripartite structure of social relations – childhood, adulthood and old age. Drawing on Hockey and James’ argument about the marginalization of children and older people (1993), disabled people are also to a large extent culturally constructed in terms of exclusion from the world of paid work, although Irwin (2003) has argued that this can be exaggerated. Independence, in particular independence achieved through employment, appears important to many people with disabilities in western societies.

Methodology

The paper employs the findings of a three-year project in the UK, funded by the Big Lottery Fund in association with the Restricted Growth Association (RGA), a membership organisation of people with restricted growth conditions. Based in three regions of the North of England, the project aimed to gain maximum ascertainment of adults with skeletal dysplasias. Recruitment relied on RGA and other disability organisations, health professionals and a variety of local media. 81 individuals with restricted growth returned questionnaires; 50 of participants took part in face-to-face interviews, of whom some subsequently completed diaries.

The sample was a diverse group with a wide range of views and experiences. Of the total, just over half (45) were RGA members. 19 respondents were male, and 62 (76%) were female: this may be at least partly explained by a greater willingness among women to participate in research of this kind. Overall, the age distribution was rather skewed towards the younger age groups, which has meant some caution is needed in interpretation of some of the findings. Over half of the group (57%) had a diagnosis of achondroplasia, and the remainder had more uncommon conditions or had not been given an official medical diagnosis (19%).

The questionnaire provided information on general personal details, education, employment, benefits, medical and health experiences and broader social issues, and incorporated a quality of life instrument. It was piloted with both RGA members and non-members from outside the project area. For those who wished, the questionnaire

could be completed by telephone contact with the researcher. The questionnaire was deliberately designed to be straightforward to complete, while providing space for additional comments and was analysed using SPSS (Statistical Package for the Social Sciences) computer software.

Interviews were carried out with 50 of the project group who had indicated a willingness to be interviewed: the interview group was constructed to reflect wherever possible the main characteristics of the wider population of people with skeletal dysplasia. Interviews used a piloted semi-structured interview schedule, and aimed to examine the main areas covered in the questionnaire together with additional issues of importance to the interviewee. They were tape-recorded and transcribed for qualitative analysis. Interviewees were also offered a chance to keep a 'diary' for 4 weeks following the interview, in which they could record relevant events and/or symptoms, or add extra comments on issues raised in the interview. These diaries were also transcribed to provide additional qualitative data. The current paper draws particularly on the qualitative data gathered in the study.

Throughout, the project the team worked closely with the Restricted Growth Association, and plans for the project were discussed with the Chair, Manager and Committee during the bid stage. Team members continued to attend RGA Committee meetings and gave presentations and workshops at the annual Conventions explaining the processes involved, encouraging feedback and giving early information about issues and findings. Dissemination events to present and discuss the project findings with project respondents and members of the RGA took place at 5 locations across the UK.

Restricted growth identity

Restricted growth is not a typical disability: the majority of people with restricted growth live independently, are intellectually unaffected, and do not face communication barriers. Few use wheelchairs. Culturally, therefore, people with restricted growth do not have many of the markers which signal membership of the disability category. Moreover, whereas in Britain, disabled people are approximately twice as likely to be unemployed as nondisabled people, employment rates for restricted growth people in this study (57%) were only slightly lower than the non-disabled average (61% according to 2001 Census). Restricted growth people generally attend mainstream, not special schools. At first glance, this suggests that restricted growth people face less discrimination than other disabled people (Thompson et al. 2008).

Data from the project suggests that identification as 'disabled' is not at all straightforward. In fact some respondents were quite vehement in their resistance to describing themselves as disabled, and were keen to emphasise their closeness to the average-size population and their distance from disability. Several traced this to parental encouragement not to think of themselves as disabled, and in common with most of society, many described disability in relation to wheelchair use, loss of faculties such as sight or hearing, or other stereotypical conditions.

“I’m just like everybody else, but just shorter, that’s how I see myself” [female, age 41].
“I’m just like everybody else, I just see myself as everybody else, I don’t class myself as, like, disabled or anything” [female, age 47].

Interestingly, many who did not class themselves as disabled in any way were in receipt of Disability Living Allowance (60%), and 56% of the sample had a Blue Badge for parking. In terms of an administrative definition of disability, they would count as “disabled”. Very few respondents, however, were involved with, or even aware of, disability rights approaches. While they could identify social barriers – such as staring and other examples of prejudices – they were unlikely to identify collectively with other disabled people. This suggests a somewhat strategic approach to the question of disabled identity, and one which we would suggest is not confined to people with this condition. What was clear was that identification as disabled rose with increasing age, but that in addition respondents spoke of ‘difference’ and ‘disability’ as much more important issues during periods of transition, and often stated that at such times they had experienced more serious issues relating to their condition.

The main problematic transitions to which people referred were starting school, the teenage years, becoming more impaired in middle age, and retirement. While three of these four life course transitions are shared with non-disabled people, their timings are often different for people with restricted growth. For example, many of our respondents reported becoming independent adults later, and becoming retired earlier, than their non-disabled relatives and peers. The different transitions experienced by these different people relate to physical, psycho-emotional, cultural and economic factors: they cannot be reduced to biology, although physical difference and medical problems play an important role. There can also be important emotional consequences.

Because it was limited to respondents aged over 18, the study did not allow us to conclude much about the first major life transition, starting school, since the accounts we received were highly retrospective. Almost all our respondents started school at the same time as their non-disabled peers. However, as for other disabled children, the move outside the family into wider society often marks the first time a person with restricted growth experiences the intrusive attention and curiosity of strangers. Difference in physical appearance at this point, however, proved less of an issue compared with subsequent moves, and few reported major problems. The youngest respondents had sometimes been supplied with adaptations at school (such as special chairs) but mainly spoke of a reluctance to use these, since they regarded them as emphasising ‘difference’ at the very time when they were concerned to fit in with peers.

Becoming adult

While few appear to have experienced much in the way of concerns about being different, or addressed issues relating to disability before the age of about 13 or 14, for many the move from teenage to young adult was a significant period from the point of view of their ‘difference’ and their restricted growth condition. This is of course a

major and often problematic transition for all young people and represents the point at which they begin to move into adulthood, involving major changes such as the move from school to employment or to further/higher education, gaining independence and extending social opportunities. In teenage years, physical appearance (and managing one's appearance) becomes more important than ever.

For the young person with a skeletal dysplasia condition, however, the situation appears to be rather different. Partly this is biological: at the point when physical attributes reach principal importance, height disparity is accentuated as peers undergo the pubertal growth spurt and then reach adult height. But more important are social and cultural factors, particularly the increasing salience of sex and relationships, together with increased participation in wider society.

Many respondents had found that just at the point when they were moving on from the school environment where relationships had been reasonably stable for some years, their physical 'difference' was producing greater incongruity when they were moving out into wider society and felt more vulnerable. Moreover, access to social activities, which may previously have been based on strong peer group ties, was for some becoming less easy to negotiate in the wider context.

"that's how it was, I used to go out with people but I'd be standing in the corner... I was the one who was holding the handbags, that's how I was classed" (female, age 51).

Lack of success with romantic and sexual partnerships was particularly mentioned as evidence of difficulties during this period, and many spoke of a sudden realisation that their condition suddenly became a much more important factor than it had previously been.

"relationships – that was probably the low point, never thinking I was going to have a long-term relationship... you're a child, you're a teenage, you're an adult, married, children, it's all set out for you in life... I would say that was the hardest years" (female, age 42).

"I found it frustrating [as a teenager] because I realised that boys didn't want to know, they just wanted a good-looking average height girl..." (female, age 47).

And as they moved into their twenties, there were often powerful anxieties expressed about social and relationship issues, and sudden realisations that their future might be different from that of peers.

"I didn't want to be the only one.... I wanted to be like anybody else really, get married and have a family" (female, age 47).

The general effect of this period was heightened anxiety over the future, and in particular concerns about the potential for finding partners, employment and independent living. A number mentioned that they had achieved these milestones at a later age than friends.

“Yes, I didn’t become independent until a lot later, a lot later” (female, age 44)
“the not knowing how to become independent. Most people at 17 are lucky, like it’s a given right for them to be able to learn to drive, to leave home, to be able to just walk into any job they want, but ...” (female, age 25).

A majority of respondents in the project had formed relationships later than their peers, for example, this man who became married in his late thirties:

“I’d not given up, but the older you get, you think ‘I’m going to be left on the shelf’”
(male, age 42).

Some felt left behind and to some extent distanced from those to whom they had previously been close.

“As I got older... the teenage years, I hated it, I hated being the way I was. My friends were fine but I felt I was losing friends because they were starting to go out with boys, I wasn’t, so I felt nobody wanted me” (female, age 45).
“I played football with my mates, but I don’t see them so much now, they’ve all got their own lives, married and children and all that” (male, age 29).

Work experiences in this period were often characterised by a concern to be seen to be able to manage all work tasks, and to maintain appearances, even if this involved a quiet struggle because of condition-related difficulties. Some respondents who had identified strongly with peers until leaving school spoke of discrimination in seeking employment, and reported that this was the first time they had felt different.

“I do feel like I’ve got to be physically strong... I don’t want to look like a wimp, you know... I do really stretch myself, I’m not a skiver” (male, age 24, working in skilled manual role).
“[I was] like everybody else... it was just when I left school and I was told I couldn’t do this and I couldn’t do that” (female, age 37).

Older adults in particular had often experienced a difficult move from school to employment and some reported reaching the point where they believed that they would not be able to work at all.

“all my friends when we left school at 14 all got jobs in factories and things, but I wasn’t allowed [by mother]” (female, age 79).
“just prior to my leaving [school] I got called into the headmistress’s study and she said ‘we’ve been thinking about what you’re going to do and I think you should stay home and help mother’, those were her words” (female, age 78).

Overall, the predominant concerns of this early adulthood period were not medical, but about beginning to realise that expectations might have to be adjusted, together

with anxiety about status, and fear of (or in some cases actual experience of) exclusion. Project respondents had found themselves at this period facing biological, educational, social and sexual disadvantage, after the first decade or more of their life when they had usually felt on a par with peers. Important 'markers' of independence: learning to drive, moving away from parents to live independently and securing employment all presented extra challenges for them, and encouraged more focus on 'difference', if not 'disability', than had previously been the case. Some reported that they had begun to believe that such things would never happen for them, and a significant number reported that they had suffered depression during this period.

"I know there was a time when I found it really hard to deal with it. And I went through a stage of, like, feeling sorry for myself I think... everybody else was starting to go out and meet boys, and nobody was interested in me... I think I struggled for a while" (female, age 39).

"Yes, I lost a lot of confidence... because I just felt I didn't want to go out" (female, age 45).

Despite apparently experiencing significant impairment, there was a reluctance at this stage to describe themselves as 'disabled', even if they were facing the question of car adaptations and benefit applications for the first time.

"it depends how you define disabled really, because although I've got bad hips and things like that and I know I'll need hip replacements [soon], I don't know whether I would class myself as disabled" (male, age 24, mobility poor, uses crutches for walking).

Transition to adulthood, for our restricted growth respondents, represented the growing realization of 'difference', in contrast to earlier closer identification with peers.

Becoming disabled

For most of the average-size population, middle age is a time for consolidation in areas such as employment, family life and status, and rarely represents any major life-cycle transition. However, for adults in the project, the time between about 30 and 50 represented an important crossing point, sometimes as a process of gradually increasing impairment effects, but occasionally through the sudden and stressful onset of spinal problems.

"... I don't cycle as much as I used to... when you get off and your legs are stiff and your joints are stiff or your back is stiff..." (male, age 45).

"and I think my back problem, pains in my legs, it's just deteriorated and deteriorated all the time, in the last 3 years" (female, age 33).

"Now I wouldn't be able to walk to the end of the street without suffering great pain" (female, age 45).

In all cases this was a crucial time when many found themselves forced to review their condition. They had to question the assumptions they had previously made about themselves, and examine the possibility that they might be 'disabled'. Although not all respondents experienced worsening of their condition at this time, three quarters of the project group were experiencing regular or chronic pain by the time they hit 40, and more than half also reported that their mobility had reduced by this time.

"My back, my spinal canal's narrowing, so they've told me, and I get muscle spasms"
(female, age 36, recently changed to p/t work).

"physically I'm not as active as I was 20 years ago... I do struggle with walking around. I would say it was more important to me now because I can't get far, I struggle climbing up on to buses. I don't know if that's just an age thing, everybody gets slower the older they get, but it has been hard" (male, age 42).

A reduction in the distance which could comfortably be covered on foot, problems with standing for any length of time, and increasing frequency and severity of joint and back pain could present a challenge to maintaining employment, and this might be accompanied by transport difficulties as well. Clearly this had wider implications, particularly for economic security, and it could be the source of some concern.

Anxieties relating to the complexity of issues connecting physical condition, employment and status were frequently reported by respondents, and many referred to the worsening of their situation as a time when tiredness increased and depression returned. Sometimes, a previously fulfilling social life was becoming restricted due to pain, reduced mobility and fatigue.

"my head says I can do things and my body can't do it, and life is a frustration and I get angry now and I never felt that before, and I get cross easier now, and that's not me and I find that hard to handle" (female, age 39).

"I get, well, what I consider depression. Because [husband's] deteriorated quite badly and our lives are changing and it's just adapting to the changes, coming to terms with the changes" (female, age 49, husband has same condition).

"I have counselling, I see a counsellor, that works wonders for me. Before that though I would say I have had quite long periods of depression, I've been on anti-depressants" (female, age 40).

"When I do go out [socially], the next morning I am usually in some sort of pain with my legs or back" (female, age 45).

Availability of medical treatment for these difficulties could be a problem: not all respondents were able to gain access to specialised medical care with practitioners who were familiar with skeletal dysplasias, and some were concerned about the possible risks involved in surgical procedures. In particular treatment for pain was rarely experienced as satisfactory.

“I’ve got terrible pains in my knees... all they’ve done is give me painkillers” (female, age 47, still working but complains of severe fatigue).

For some their work was beginning to be affected, and this had had repercussions for other areas of life and raised anxieties for the future. And some felt that surgical options for remedying problems carried such an element of risk to their general condition and to their employment that they preferred not to take them.

“I’m still living at home with my mum, can’t afford to do otherwise, especially without working. And then the injury at work and it’s had a knock-on effect, my confidence has dropped, my social life has gone down” (male, age 31: back problem at work led to a diagnosis of spinal stenosis associated with his condition and advice to leave job).

“They said they could do an operation now, but it could affect my muscles and my ligaments in my elbow, and that would put me out of a job” (female, age 30, experiencing pain and loss of function in arm).

“they’ve given me the opportunity to have a major back operation, but the chances of that – you could end up in a wheelchair, so I’m opting out of that at the minute” (female, age 33).

A further problem respondents could face at this stage was that of excess weight. This was closely related to reduced mobility: exercising had become more difficult, and other factors such as depression and increasing isolation, had produced a spiral from which it had become difficult to escape.

“I put a lot of weight on with not going out... just I couldn’t be bothered, with having problems with the back” (female, age 45).

“I’ve put on a lot of weight recently... throughout my life and since I’ve learned to drive I started to put on weight, because suddenly you go from A to B in the car” (female, age 43).

“But it is hard, obviously with my back it’s a vicious circle, if my back’s hurting I can’t exercise, if I don’t exercise I put on weight, which obviously makes my back worse, so...” (female, age 41).

Midlife, then, was a time when medical issues had become more important for many respondents, with associated risks to employment and income, independence and participation, and social status. Some expressed fears for the future, either because they worried about potential deterioration in their condition, or because they were already experiencing problems and were concerned that these would worsen with time.

“[I] don’t want any pain [in the future], having got away with it for 45 years, apart from slight backache [and] real back pain soon after I got married... so I don’t want that again, though it may happen” (male, age 45).

“at the minute I’m one of the lucky ones... everything is fine at the moment, touch wood, I don’t really want to end up in a [wheel]chair” (male, age 35).

Whereas many respondents had previously resisted the idea that they had a disability, they now wondered whether it was an appropriate description, or else had accepted the label largely as a result of increasing impairment effects. Ironically, even if they had functional limitations and saw themselves as disabled, many applications for Disability Living Allowance had been turned down on the basis that the applicant did not qualify. This provides a useful illustration of how people with unusual mobility limitations like skeletal dysplasias often fail to ‘fit’ the requirements of welfare benefits.

Becoming old

While the processes of ageing and retirement are universal, and age-related disability is common, those with restricted growth experience these developments at an earlier age than their non-disabled peers. While medical symptoms – particularly spinal and joint pain and restricted mobility – can occur at any age, only about a quarter of respondents failed to report such problems by the time they were in their fifties. Moreover, the scale of physical difficulties were usually more serious and restricting than the every day “aches and pains” which peers may experience. Overall, respondents experienced reductions in mobility and increases in chronic pain, with associated consequences for their employment, day-to-day living and social life.

“I was very outgoing before, I did everything... [but] I haven’t got the strength now to walk round to [X]’s because of my legs being weak, they just start going at a certain stage after I’ve been on them for a while, so I have to get the bus round there, you know, just little things like that. I mean, it’s only a 5-minute walk really” (female, age 56).

“It’s only really since I’ve had to retire that I’ve really realised what the problems [with achondroplasia] are, and the problem is not the legs, it’s the reach with the arms, it’s a problem which I’ve never noticed before” (female, age 55).

A high proportion of the older respondents reported that they had retired early or were likely to do so, and more than half had done so specifically on health grounds. This had been a severe blow, especially where work had been an important source of status and social life.

“Well [retirement] might be forced upon with me with ill health myself, it depends how long my spine holds out, doesn’t it? ...” (female, age 49, working part-time).

“... because I’d have liked to work till I was 65. That’s annoyed me, that I can’t... that was hard to accept” (male, age 57, retired due to ill health at 52).

“I had to stop teaching [12 years ago].... I became a pensioner.”

Interviewer: “Did you decide that?”

“No, I didn’t in the first place, no. It was sort of put to me at school ‘you’re finding it more difficult, aren’t you?’ and I said yes... [but] I didn’t want it. I missed teaching the children and I honestly felt that [my teaching] wasn’t being jeopardised” (female, age 60).

Early retirement when it had occurred had sometimes been abrupt, and had often been encouraged by employers on the grounds that the requirements of the job could no longer be fulfilled, and was met with mixed feelings: the losses involved had to be weighed against the pain, declining mobility and increasing fatigue.

Financial concerns were particularly important, and this was especially so since older adults in the project group had experienced difficulties in gaining employment in the first place, or had found it impossible to secure employment at a level commensurate with their skills. There was evidence across the project group of a concentration of employment in low-grade occupations and little career improvement (Shakespeare et al. 2010), both of which are likely to have a negative effect on financial position in retirement. Unsurprisingly a strong sense of loss characterized respondents' comments relating to this period.

“Retirement meant losing what I had worked for all my life” (female, age 55, who had fought very hard to get accepted for nurse training and succeeded).

Other important issues at this period included depression and increasing isolation and loneliness.

“I don't work now because of the back problem. I find some days I can be all right and some days I just find it so hard at the moment, and then doing things, I just don't go out if I feel like that. Social wise I try to get out and about... but I find that because of the back trouble I tend to make it an excuse not to go out” (female, age 45).

“The GP just said to me ‘are you depressed?’ and I said ‘of course I am... I know what the depression is caused by, I'm in pain, I'm in discomfort, that's what's causing it, I don't need tablets, I know what the problem is, I need the problem solving’” [begins to cry and apologises] “It's so frustrating” (female, age 55, mobility has worsened recently and efforts to deal with chronic pain have been unsuccessful).

During this period, respondents emphasized feelings of difference and were more likely to identify as disabled.

“Yes, now I would [describe myself as disabled]. But 10 years ago, no” (female, age 50, recently took early retirement from office job).

As well as anxieties around work and money, respondents again feared physical deterioration and its consequences for their lives. The differences in experience between the project respondents and their peers is perhaps most acute at this period.

For most non-disabled people, retirement can be seen as the beginning of a period of new and exciting pleasure-based challenges and is positively anticipated and planned. In the general population, there is some evidence of declining rates of disability in the decade after retirement (Manton et al. 2006). For our project respondents, however, fear of declining physical condition, the loss of status associated with retirement and

the enforced loss of the social element of work, together with increasing isolation due to declining mobility, represent a stark contrast.

Conclusions

This study contributes to the growing emphasis in British disability studies on the role of impairment in the lives of disabled people (Shakespeare 2006). We believe that this data shows the value of disaggregating disability and focusing on a specific impairment group, although we concede that similar processes may be evident in the lives of people with other disabilities. We have tried to show how social relations, cultural expectations, and impairment effects are entwined for people with restricted growth. Skeletal dysplasias are highly visible congenital conditions and they also have some of the features of acquired or degenerative conditions, particularly the negative psycho-emotional impacts. Whereas our respondents did report experiences of discrimination and prejudice – for example, stares and physical harassment – we have concentrated here on how poor health also influenced their lives. In terms of life course transitions, health status appeared to be the key element in identification, rather than any wider social reactions. Perhaps because the restricted growth community seem to be insulated from wider trends in disability activism, we could not trace the impact of disability rights or social model perspectives in the language or identity choices of the majority of the participants.

Among the implications of the study is the need for health services that respond more effectively to the medical complications of skeletal dysplasia. People with restricted growth themselves should avoid occupations which might exacerbate future physical deterioration, and try to preserve fitness wherever possible, and more flexible working arrangements and more accessible environments will support continued social participation. Across the age range, but particularly in the teenage years, psychological support and peer networks may have value in promoting self-esteem and social inclusion. Where possible, advance planning which takes into account potential reduced earning capacity in later life may be advisable for people with restricted growth.

In terms of disability identity, this data shows that the same condition can be understood differently by different people, and by the same person at different periods of life. Adults with restricted growth are an unusual group: they are born with a rare and heterogeneous condition, and many have little contact with others with similar conditions. This in itself may be one reason why they often fail to identify with the disabled label, at least until they experience pain and mobility difficulties, and why some may reject the skeletal dysplasia condition as a key factor in their identity. Whereas many people with impairments prefer not to identify as disabled, sometimes they are forced to confront the reality of poor health and increasing restriction and exclusion.

The benefits of taking a life course perspective is that it shows how disability is not a static situation but rather a dynamic interplay of medical, social and cultural factors. In addition, we would suggest that transition periods are points at which issues

relating to 'difference' and disability become more sharply focused, and these are times when support needs are greatest, especially given the evidence of higher rates of depressive illness at these times. In terms of life pattern for this group, the chronological events may occur, but at a different point from the average-size population. Independent adult life is compressed into a shorter period: social milestones such as independent living, long-term relationships, marriage, etc. often occur at a later age, whereas biological old age often begins at earlier age. This is in marked contrast to the trends of earlier maturity and later senescence for non-disabled people over recent decades and further accentuates the difference of disability.

Note

Sue Thompson has a background in social policy and medical sociology, having conducted research with people with Parkinsons Disease, among others. Tom Shakespeare is a sociologist with a particular interest in disability, now working at the World Health Organization. Michael Wright is a clinical geneticist in the NHS, and director of the Northern Genetics Service, as well as President of the Restricted Growth Association. Thanks are due to the Big Lottery Fund for supporting the research, and to the Restricted Growth Association for managing the study, as well as to the editors and reviewers of this special issue for their helpful feedback. E-mail Sue Thompson: thompss@wou.edu.

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