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Disruptive illness contexts and liminality in the accounts of young people with Type 1 diabetes

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Subject Area:	Chronic illness, long-term illness < RESEARCH AREAS, Diabetes < RESEARCH AREAS, Biographical disruption < RESEARCH AREAS, Adolescence < RESEARCH AREAS, Qualitative methods generally < METHODS AND METHODOLOGY
Abstract:	<p>We utilise Bury's (1982) biographical disruption to examine young people's experiences of type 1 diabetes. Our findings show that young adults adopted various 'subject positions' across different illness contexts. The subject positions deployed are intended to produce a particular kind of normal embodied identity unaffected by diabetes. First, participants concealed their illness in public spaces and challenged cultural stereotypes of diabetes to maintain a normal illness biography. Disruption was ever present and required careful negotiation to avoid exposure of illness in public. Young adults upheld a 'normal public presentation'. Second, they resisted the medical system's pressure to adhere to glucose targets asserting and maintaining a subject position of 'independent and autonomous young adults'. Here, disruption was transient and temporary, present in the clinic but not always beyond. It remained in the background for much of the time until it was reinforced by parents or at meal times. Third, young adults acquired a 'pragmatic subject position' with diabetes viewed as complex but manageable, no longer a target for resistance. Frank's (1995) 'narrative restitution' is adopted to describe the transition to life with 'normal' illness. We argue that illness experience was 'liminal' and reflected the subject positions adopted by young adults.</p>

Disruptive illness contexts and liminality in the accounts of young people with Type 1 diabetes

Abstract

We utilise Bury's (1982) biographical disruption to examine young people's experiences of type 1 diabetes. Our findings show that young adults adopted various 'subject positions' across different illness contexts. The subject positions deployed are intended to produce a particular kind of normal embodied identity unaffected by diabetes. First, participants concealed their illness in public spaces and challenged cultural stereotypes of diabetes to maintain a normal illness biography. Disruption was ever present and required careful negotiation to avoid exposure of illness in public. Young adults upheld a 'normal public presentation'. Second, they resisted the medical system's pressure to adhere to glucose targets asserting and maintaining a subject position of 'independent and autonomous young adults'. Here, disruption was transient and temporary, present in the clinic but not always beyond. It remained in the background for much of the time until it was reinforced by parents or at meal times. Third, young adults acquired a 'pragmatic subject position' with diabetes viewed as complex but manageable, no longer a target for resistance. Frank's (1995) 'narrative restitution' is adopted to describe the transition to life with 'normal' illness. We argue that illness experience was 'liminal' and reflected the subject positions adopted by young adults.

Disrupted illness biographies

Bury (1982) introduced the concept of 'biographical disruption' to denote how illness leads to a breakdown of normality in the structure of people's lives. This impacts on sense of self and leads to redefinition of, and adjustment to the change in circumstances. A previously illness-free self requires readjustment and renegotiation in relation to relationships and social activities. Bury's concept outlined what subsequently became the focus of scholarly debate resulting in somewhat polarised accounts in which chronic illness (more commonly referred

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3 to today as a 'long term condition', which drops the assumption that a progressive illness
4 necessarily has to be 'chronic') is either disruptive or not disruptive (Pound et al 1998;
5 Larsson and Grassman 2012). Perhaps in anticipation of such polarisation Bury (1988) later
6 included the concept of illness significance and consequence, to stress the multidimensional
7 nature of illness experience. This seemed to be a turning point in the intellectual debate
8 inviting more sophisticated conceptualisations of illness. The distinction was applied to
9 highlight both how people 'make sense of' and directly 'experience' illness (Sanders et al
10 2002). When placed in the context of older age the meanings take on a different form, with
11 biographical disruption questioned and redefined. A significant body of sociological literature
12 evolved from Bury's ideas which might be divided into parallel lines of enquiry with illness
13 experience viewed as either normal, disruptive, or both.
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28 The literature on 'biographical disruption' has predominantly examined the experiences of
29 'older' people. There are a few exceptions, however, that report the accounts of younger
30 groups which we discuss below (Saunders 2017). Since the 1990s the notion of 'normal
31 illness' has been well articulated to illustrate how disease does not automatically lead to
32 disruption in the way that Bury claimed. For instance, if examined in relation to social context
33 'disruption' might be negated or avoided. Williams (2000), showed how disruption resulting
34 from illness was anticipated by people in the context of economic adversity, which in turn
35 reduced its impact. Likewise, Carricaburu and Pierret (1995) found that homosexual men
36 viewed contracting HIV as 'biographical reinforcement' since it offered a sense of belonging
37 and membership of a community of men diagnosed with HIV. Similarly, 'biographical flow'
38 extended the normal illness argument with stroke representing a continuation of biography
39 rather than a disruption to it (Faircloth et al 2004). In much of the published research on
40 biographical disruption the context of ageing features prominently in people's accounts. The
41 connotations of ageing, which include physical decline are assumed to play a prominent part
42 in how people define ill health as inevitable. Pound et al (1998) reported that physical and
43 mental decline was viewed by stroke survivors as an inevitable part of ageing over which
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3 individuals exercised little control and were compelled to accept. The narratives of normal
4 ageing led the authors to conclude that stroke survivors do not in fact experience
5 biographical disruption.
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11 The normal illness thesis has subsequently been challenged by authors seeking to
12 demonstrate a more fluid theorisation of illness experience, with normality and disruption
13 interconnected not separate. Disease can still be disruptive in old age, and people's
14 responses need not be wholly 'passive'. Sanders et al (2002) found that normal and
15 disrupted accounts coexisted in people with osteoarthritis. Pain and disability were both
16 normal and disruptive. The increasing fluidity in how accounts of chronic illness are
17 presented in the literature gives rise to the importance of context and contingency where
18 illness may increase, decrease or even disappear, described previously as a state of 'shifting
19 normalities' (Sanderson et al. 2011). Saunders et al (2018) report 'biographical suspension'
20 in people with sciatica, whose anticipated future recovery from pain, often perceived as
21 temporary, gave rise to a state of liminality which manifested in different types of
22 suspension. Much of this 'suspended' disruption can be explained by the perception that
23 sciatic symptoms are an injury not a disease and therefore temporary. Monaghan and
24 Gabe's (2015) study of children with asthma depicted illness as largely unremarkable and
25 only disruptive at certain junctures. Whilst Larsson and Grassman (2012) claimed that the
26 general 'anticipation' of developing chronic illness in old age did not mean that people
27 viewed it as normal. Following in this vein, Saunders (2017) presents young adults with
28 inflammatory bowel disease as experiencing recurrent disruption, which is intermittent and
29 unpredictable. Disruption here is conceived, not in terms of a single disruptive event such as
30 a 'flare up', but as a pattern of cyclical and recurrent disruption caused by the disease. The
31 two young adults in this study learnt to accommodate the anticipation of relapse; the
32 recurrent pattern almost viewed as a personal resource with which to prepare for future
33 disruption. Saunders (2017) further illustrates the co-existence of normal and disruptive
34 biographies shifting between each other. Long periods of normality without 'flare ups' are
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3 replaced by intense phases of recurrence and disruption moving in and out of focus. The
4 disease was not all consuming but characterised by fluctuating patterns of latency and
5 relapse.
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11 The concept of liminality has previously been deployed to depict these fluctuating patterns to
12 describe the tension brought about by illness onset, with people negotiating their pre and
13 post-diagnostic identities where the self-concept shifts. Liminality is a situation where
14 individuals do not fit into any one space, classification or definition, but somewhere in
15 between. They may have a diagnosis but do not experience illness or shift between a normal
16 and abnormal illness identity. It is neither a state of illness or wellness as in the case of
17 chronic fatigue (Brown et al. 2017). A cancer diagnosis could reinforce negative risk
18 perceptions of recurrence or mortality, preventing a return to life as normal (Trusson et al.
19 2016). Liminality is an existential state rather than a passing phase. People experience
20 liminality but also actively negotiate illness to assert some control over illness uncertainty.
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22 Saunders et al (2018) found that people with sciatica rejected their diagnosis as representing
23 'the real me', sometimes leading to proactive illness management to assert control over
24 symptoms. Similarly, dementia could lead individuals to move into a post-liminal state as
25 either active or passive citizens in the way they respond to the illness (Birt et al. 2017).
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43 **Type 1 diabetes, young adults and chronic illness**

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45 Management of type 1 diabetes in young adults particularly during the transition from
46 paediatric to adult care is challenging and often results in poor clinical outcomes (Barnard et
47 al 2014). This is a long-term condition often diagnosed in childhood or adolescence. The
48 effective control of blood glucose is critical to avoid long term complications such as
49 blindness, limb amputations, and kidney failure (Knight et al 2005). Consequently, the
50 challenge is to attain good control of blood glucose, which is problematic in young adults
51 transitioning from paediatric to adult services. As they move to adult diabetes care they are
52 eventually expected to assume greater independence over disease management, away from
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3 reliance on parents. This process can present a tension in the way they adjust to their
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5 illness, assuming more responsibility and navigating the healthcare system. Type 1 diabetes
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7 places almost unique demands on the individual. Long term conditions such as HIV or stroke
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9 in older people or even malignant disease which is often slowly progressive is essentially a
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11 passive process in terms of minimal self-management. In contrast, type 1 diabetes places
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13 huge demands on the individual both in terms of skills (calculating insulin dose, measuring
14
15 blood glucose etc). If they get it wrong, either their glucose falls below normal and they
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17 experience hypoglycaemia which can lead to confusion or coma, or their glucose runs high
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19 and, over time, there is a risk of long-term complications. During childhood, it is the parents
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21 who bear the responsibility (usually the mother). But during adolescence they need to learn
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23 and implement these complex self-management skills. Thus, in the short-term if they get it
24
25 wrong they risk hospital admission, death, significant hypoglycaemia, impaired cognitive
26
27 function, loss of consciousness, and embarrassment in front of friends. This means acquiring
28
29 many skills that non-diabetic friends are not burdened with. Self-management is not as
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31 simple as using an inhaler when feeling breathless. They need to do this every day even in
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33 the absence of symptoms. Symptoms of breathlessness, pain, decreased mobility as in
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35 some cancer diagnoses usually drive people do something proactive. A sub-normal glucose
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37 level (asymptomatic) does not.
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44 Much of the literature on young adults with type 1 diabetes presents illness experiences as
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46 characterised by a desire to lead a normal life. The reality of daily living, however, is
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48 influenced by ongoing interference of diabetes. In relation to the concept of biographical
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50 disruption, young adults' attempts at detachment from the disease are met by constant
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52 reminders that life with diabetes is anything but 'normal' (Schur et al 1999). The negotiation
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54 of diabetes alongside the pressures of youth is conducted with various degrees of success.
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56 The co-existence of normal and disrupted biographies in the context of older age are equally
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58 evident in relation to young people with type 1 diabetes. Research shows that parents and
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60 young adults with Type 1 diabetes engage in a trade-off between leading a normal life and

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3 enforcing self-discipline to control the disease, by injecting insulin at the right time and
4 avoiding certain foods; a price thought to be worth paying for the benefit of reduced relapse
5 and therefore disruption to family life (Marshall et al 2009). A finding echoed in Miller's
6 (1999) study where self-discipline around glucose control appeared important and a sacrifice
7 worth making for keeping symptoms under control. In one sense the family context seems to
8 provide stability and protection from the disruption caused by diabetes. In another, it
9 reinforces glucose control regimes which may in themselves cause disruption to young
10 adults but offer a sense of stability and reassurance to parents that the disease is being
11 properly managed. In a study by Hatton et al (1995) the stress of living with the condition
12 required ongoing control and inflicted long-term disruption to both parents and young people.
13 Whilst for Dovey-Pearce et al (2007) the daily disruption of diabetes symptom *control* was
14 tempered by the safe base of the family, which had a protective effect for young people
15 providing safety and security in the face of relapse. It is of note to distinguish between
16 disruption caused by the *disease* and the *effort* surrounding symptom control. Peer support
17 has also been shown to buffer the negative experiences of diabetes such as improved
18 control of illness disclosure in public. Integration into a larger peer group may render the
19 disease less visible perhaps. Others yet show how the tension between diabetes control
20 regimes and conformity to expected student norms at university inevitably led to trade offs.
21 The typical student experience was characterised by a varied blend of living life both as
22 normal and disrupted. Depending on the circumstances the tension was resolved in different
23 ways; at times in favour of glucose control where adherence to a regular dietary programme
24 outweighed the need to conform to university culture (drinking, socialising), at other times
25 the converse. Here biographical disruption could be described as 'ever present' though to
26 different degrees, negotiated according to the immediate circumstances the young person
27 finds themselves in. All of this is viewed as an attempt to construct or maintain a 'moral self'.
28 Balfe (2007) found that university students with type 1 diabetes engaged in 'body projects' to
29 establish control over illness by presenting a moral narrative; that is for instance, the goal of
30 eating appropriate food and well measured quantities in order to reduce weight and conform
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3 to societal body image stereotypes, not to protect themselves from future health
4 complications. The context of the university had a major impact on how participants
5 negotiated their identity body project, and the constant pressure to balance both. This
6 literature suggests that the management of potential future or immediate disruption was a
7 proactive exercise, not passive as sometimes depicted in relation to older people with
8 chronic illness (Pound et al 1998). Balfe (2007) found gendered repertoires of subject
9 positions, where males were more disciplined in their glucose control regimes as these fitted
10 with their moral narrative of the ideal masculine identity, since dietary discipline aligned more
11 comfortably with participation in sports and physical activity leading to an ideal body shape.
12 Females' subject positions (of a thin body image, for example) were less well aligned with
13 the glucose control regimes that demanded a disciplined dietary routine (eating certain
14 foods, right quantities, at the right times). Previous literature has also shown that in addition
15 to the desire to 'fit in' a social context and achieve the required trade off with maintaining
16 optimal glucose control, other social processes such as stigma may come into play, where
17 young people become stigmatised and socially isolated as a result of their condition (Dovey-
18 Pearce 2007; Schur et al. 1999).

39 **Youth transition**

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41 It is important to appreciate how individuals move from childhood to adulthood as a basis for
42 explaining illness experiences. Traditionally, adult transitions have been studied by
43 academics interested in youth 'geographies', but much of this work has applied a static
44 conceptualisation of transition based on linear temporal phases and movements across time
45 (Butcher and Wilton, 2008; Valentine, 2003). Allport (1955) and Grosz (1999) showed how
46 the concept of 'becoming' can be used to consider the inherent complexities of
47 contemporary youth transitions. Arnett's theory of 'emerging adulthood' describes a distinct
48 stage of the life course where young people have left the dependency of childhood but not
49 yet assumed the responsibilities of adulthood (Arnett, 2000). Giddens' (1991) ontological
50 security can help to conceptualise how young adults negotiate chronic illness in the context
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3 of youth transition, a time often characterised by pressure to normalise illness and find ways
4 of integrating a disrupted biography into a 'practical consciousness'; everyday routines to
5 reinstate a normal sense of self.
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10 11 **Methods**

12 ***Setting and participants***

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14 The qualitative study was conducted in the context of a structured education programme
15 (Working with Insulin, Carbohydrates, Ketones and Exercise to Manage Diabetes –
16 'WICKED') delivered at two different sites: a village hall (Site A) and a seminar room at a
17 hospital (Site B) designed to facilitate shared learning and self-management among young
18 adults (16 to 24 years old) with type 1 diabetes. The aim of the study was to explore the
19 acceptability of the course, reported in a separate paper (see Sanders et al 2018). We
20 explored the individual and collective experiences of young adults towards managing their
21 diabetes and the key obstacles to effective self-management at a key point in their transition
22 towards adulthood. Interviews were conducted twelve weeks following each course in the
23 homes of the study participants, whilst focus groups were conducted at two course sites.
24 Focus groups were convened on the final day of the course. A total of 17 participants
25 attended Site A and 15 attended Site B, yielding a total of 32 attendees (all attended focus
26 groups). We therefore recruited a total of 15 young people to an interview, approximately
27 50% of all attendees. Average time since diagnosis was 9 years in all interview participants.
28 Eight girls/women and seven boys/men were interviewed, and the average age was 18.
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49 ***Interviews and focus groups***

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51 We conducted 7 focus groups immediately after each WICKED course with the participants,
52 and 15 interviews twelve weeks following the course. Interview participants were sampled
53 purposively based on maximum variation to ensure broadly equal proportions. All
54 participants were invited to participate in focus groups following each 5-day course, thus the
55 focus group data is representative of all participants attending the WICKED course. The
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3 interview and focus groups were audio recorded and transcribed. The data were coded and
4 analysed thematically using a combination of N-vivo 10 and manual coding techniques. The
5 data were coded independently by two members of the study team (a senior medical
6 sociologist and a research health psychologist). Regular meetings were held to discuss and
7 compare the coding and the emerging findings. Interviews and focus groups explored similar
8 topics including the experiences of attending the course and attitudes towards diabetes self-
9 management before and after completion of the course.
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20 Our approach to analysis was informed by the principles of grounded theory, particularly the
21 constant comparative methodology (Strauss & Corbyn 1994). This included immersion in the
22 data to identify the major themes, following which we compared data extracts in search of
23 similarities and differences. Themes were developed using thematic coding, where both
24 researchers assessed the most highly recurring views to explore in more detail. Although we
25 used semi structured methods, we tested earlier findings in subsequent interviews. The
26 themes were also examined using theoretical concepts such as biographical disruption and
27 to what extent and in what way did the experiences of participants reflect some of the key
28 constructs relating to this theory. We eventually arrived at three dominant themes, which
29 forms the basis of our paper, and analysed these in further depth to explore how public
30 spaces, attendance at clinics and assimilation of complex knowledge about diabetes led to
31 illness disruption. We examined negative cases such as the absence of biographical
32 disruption in the data.
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50 As each researcher came from a different discipline (sociology and psychology), the findings
51 were interpreted using slightly different conceptual frameworks, although through discussion
52 the interpretations converged. This prompted critical reflection on the early interpretations
53 with a view to examining the data in search of examples in the interviews which supported or
54 refuted them. Reflection was also facilitated by the lead researcher's (sociologist)
55 attendance at the courses, which informed interpretation of the interview and focus group
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3 findings. Much of the discussion during the course offered insights with which to interpret the
4 analysis. Data saturation was reached when no new ideas or insights were found in the data
5 analysis. We analysed the focus groups first, which is why we reached data saturation after
6 fifteen interviews. The key themes were identified early on from the focus groups, which we
7 explored further in the interviews, and decided to stop data collection at this point when no
8 new insights emerged.
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18 **Results**

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20 The findings present the negotiation of normal and disrupted biographies by young adults
21 with diabetes. We use the notion of liminality to illustrate the fluctuation of illness
22 experiences between disruption and normality depending on the context.
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28 **'Nobody knows what it's like to be me'**

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30 As type 1 diabetes affects just 10% of all cases of diabetes, with type 2 the most common,
31 participants struggled to place their experiences in a broader context, leading to feelings of
32 isolation. A major frustration was the view that young adults are often labelled as different or
33 perceive that they are different. This seemed to be an important obstacle to their transition
34 into adulthood as they tried to present a 'normal' self in public. It required ongoing
35 awareness and anticipation of when they may experience a sudden deterioration in glucose
36 levels that could risk exposing their illness to others.
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48 Yeah. There's a quote I found on the internet 'A lion will not understand a zebra until
49 a lion becomes a zebra for a day'. Which kind of means you can talk to someone as
50 much as you like but if they don't understand or they don't have what you've got they
51 won't understand at all. So the best person to talk to is someone who actually has it
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56 (Interview, 008, male, 16, Site B)
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3 If you were like oh yeah I didn't do my insulin purposely because I didn't want to be
4 well. That ... like you would feel judged. Like somebody outside would be why the
5 hell are you doing that, that's like somebody with a broken foot going oh I'm going to
6 go and play football though even though my foot's broken. Like it doesn't make sense
7 to people that whilst you're sat in a group with other diabetics they get that. They're
8 like oh yeah I've felt that way. (Interview, 003, female, 21, Site A)
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18 Young adults reported the less tangible benefits including listening to others' experiences
19 and challenges of living with the condition, to help find their own 'level' within the group.
20 Lawton and Rankin (2010) showed that patients 'recalibrated' their risk thermostats based
21 on the insulin dose adjustment experiences of others. The literature shows that social
22 networks can provide emotional and practical aid as well as facilitating a means to mobilise,
23 negotiate, mediate and access further assistance (Reidy et al 2018; Kennedy et al 2016;
24 Hempler et al 2016). A supportive social network is known to have a "buffering" effect in
25 situations eliciting stress, such as the introduction of a complex new technology (Blickem et
26 al 2013; Harrison et al 2014). This seemed to help them normalise their glucose
27 management behaviour and acknowledge it as acceptable, rather than something to be
28 ashamed of. Not being understood by others who were unaffected by diabetes led to
29 feelings of isolation and detachment. It also led to concealment of the condition from others
30 in anticipation of the negative public assumptions surrounding diabetes.
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47 That's what most people are like though. Most of them just go 'oh so you can't have
48 sugar' and then I just sort of... well I bank my head against a wall. The worst thing is
49 when someone says 'is that the one for fat people Type 1 or is that Type 2?' I'm sat
50 there thinking oh my god that's not very politically correct is it (Interviews, 004,
51 female, 18, Site A)
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3 So if we normalised it and it isn't our fault it'd be a lot easier and people wouldn't get
4 misconceptions about it which if a lot of people have the same misconception can be
5 really frustrating and annoying for us to have to deal with and to have to explain
6 every single time (FG, male, Site B)
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13 Some expressed a desire to hide their diabetes by refusing to inject in public. Valentine's
14 (2003) 'performativity' alludes to how young people 'act out' their 'subjectivity' in public, in
15 this case to be perceived as a 'normal' young person.
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22 It helps you feel more like... I don't like to use the word normal person, but everyone
23 with a sort of disability or disease or anything like that, I don't want to say it in a bad
24 way but they don't want to feel they've got it... everyone wants to sort of, kind of,
25 yeah not be like they've got something wrong with them and talk about things freely
26 (FG, male, Site B)
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34 Whereas Type 1 it's not our fault at all. We don't know what causes it but its not due
35 to being overweight or anything like that and that stigma that's attached itself to Type
36 1 because people don't know the difference it can be quite... it's really negative and it
37 can impact on you like psychologically and the perception of yourself cos of
38 everybody else's misconception (FG, female, Site B)
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47 Blame featured strongly in our participants' accounts and led to concealment of behaviours
48 that could reveal the illness, signifying a disruption to self and identity. Self-medication in
49 public spaces was perceived as socially undesirable leading to stigmatisation.
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55 A. But it might be because we go into private places to inject so that's why people
56 aren't as accepting.
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3 B. I just feel because there's less cases of Type 1 diabetes than Type 2 and even
4 with Type 2 there's very few that are actually on insulin injections for Type 2 so
5 it's a lot less common than... Maybe people carry round inhalers just for the...
6 just like as a safeguard but they never actually seem to use it but everybody
7 knows that an inhaler is safe and that its normal whereas again injections aren't,
8 whatever equipment that nobody else seems to have that you might have if
9 you've got a pump, they don't understand why that is. And other people, when
10 they go out to town, they barely have anything with them. You always have to
11 have a bag and they don't... it's just those little things (FG, female, Site B)
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24 I used to hold back and put a guard up and like 'no I don't want to hear the word
25 diabetes, I don't like diabetes'. I was embarrassed about what I had and even if
26 someone mentioned diabetes I was like no stop mentioning this, change the
27 subject. (FG, male, Site A)
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35 Young adults experienced biographical disruption (Bury 1988) which they attempted to
36 manage through hiding their condition in public by not injecting insulin and thus making the
37 visible invisible. Disruption posed a threat to self and identity and was clearly present but
38 accommodated through 'concealment'; a necessary precaution to 'fit into' public spaces and
39 normalise the illness. A dialectic relationship is evident in the struggle to maintain a 'normal
40 externally facing self'. There is disruption to biography, but that is carefully and sometimes
41 haphazardly managed to maintain a normal self in public. The young people are ever
42 conscious of their diabetes but push towards a normal self-presentation (Goffman 1959).
43 They do not reach a state of complete normality in this context since the diabetes is ever
44 present and requires constant planning to avoid outwardly manifestation. A state of liminality
45 is evident; neither is their illness normal or disruptive. Disruption is controlled through
46 concealment. Normality is maintained only in public view; in private such concealment may
47 be unnecessary, and therefore only must be managed in social situations. To our young
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3 adults, disruption is always present, either safely tucked away in the background or
4 threatening to reappear at the most embarrassing moments. Similarly, Balfe (2007) reported
5 the trade-off students make between tight control of glucose regimes and the desire to
6 participate in student culture, with the latter often winning the day. For our young people
7 participation in social life meant a similar trade off had to be made.
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15 Young adults make choices to manage embarrassing or difficult social situations that carry
16 future health risks, in an attempt at 'colonising the future' (Giddens 1991). These decisions
17 however are not 'passive', miscalculated or misunderstood, but based on an evaluation of
18 risks and decisions that have meaning, and help preserve their public (image) identity as
19 'normal' young adults (Valentine 2003). In this situation disruption is defined by exploration
20 of possible futures (Arnett 2000) and a desire to lead a normal life, and careful consideration
21 of what they want to 'become' (Arnett 2000). The need however for safe(r) glucose control
22 will manifest eventually and demand a response, fuelling the cycle of disruption and the
23 presentation of a 'normal' self in everyday life. In this public presentation of self, we can
24 define the illness experiences of young adults as managing the cycle of biographical threat.
25 They were more concerned about identity than the risk to health. As Giddens (1991) might
26 concede, colonising the future is about managing the self in everyday life, or as Balfe (2007)
27 contends in relation to the maintenance of 'subject positions' by people to help construct a
28 moral narrative. The subject position constructed by our young people involved presenting a
29 'normal self' in public spaces, helping to counteract illness disruption. Biographical disruption
30 here is neither dominant or latent, but ever present, and characterised by 'liminality';
31 'backgrounded' in public spaces at least for the time being, only to resurface in the relative
32 safety of home. Diabetes was never described as overwhelming (total disruption) or normal
33 (undisruptive) but occupied a middle ground.
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58 **'It's me against the (medical) system'**
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3 Target driven glycaemic control reinforced by the medical system was viewed as a major
4 disruption preventing young adults from leading a normal life. The following narratives refer
5 extensively to the medical pressure to maintain optimal glucose control and concur with the
6 demands of the (medical) system driven by targets. Young adults reflected on the
7 discordance of target driven medical care with their own self-identity as autonomous and
8 independent agents of change (Giddens 1991). Many claimed that the medical system was
9 preventing them from living a 'normal' life; encouraging short term sacrifice for long term
10 clinical benefit.
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22 I don't know it's just maybe the everyday things like how people are always asking
23 questions or they stare whenever I check my blood sugar or something. I don't know
24 just being able to, if not relate, then just tell someone about it who will understand a
25 little bit that... I don't know. (Interview, 007, female, 17, Site B)
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32 They (clinicians) do personalise like different numbers according to how well you're
33 doing like my HbA1c is always above what the government sets but it's still better
34 than what it could be and they know that like life kind of does happen and things...
35 aren't always able to do everything that they ask you to and would like you to do in
36 an ideal world where you didn't have work, school, days out things like that that can
37 affect different things, stress, illness or anything like that. But sometimes it can be
38 difficult talking about your problems to clinicians (FG, female, Site B)
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50 The structured education programme had implications for patient self-management and
51 interactions with the healthcare system. The findings revealed a contradiction between
52 young adults' interactions with the healthcare system and maintaining their own sense of
53 autonomy.
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3 Most endocrinologists I feel they don't understand the emotional side of the disease
4 but all the nurses they seem to have more of a relationship with all of us and have
5 more of an understanding of what we go through emotionally and every day
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9 (Interview, 007, female, 17, Site A)
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13 I want to do it my own way. I don't want to be forced to look at a graph, see what's
14 good, what's bad and keep doing that like (Interview, 008, male, 16, Site B)
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20 if I'm having a difficult time in my life I'll get worse control. But just going to clinic I
21 don't feel like that's... I don't get the sort of message that that's normal so it feels like
22 I'm doing bad (FG, male, Site B)
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28 Similarly, they distinguished between diabetes as both a physical and a 'lived' experience.
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32 I suppose the importance of keeping it in... your blood sugars in the target range and
33 the effects of not keeping it in your target range and I suppose the importance of that
34 was explained which makes it more... rather than just the consultant saying you need
35 to keep it in the target range, this is....., you need to do this. There's a reason behind
36 it and sort of like you've got an understanding of why it needs to be like that. You
37 understand almost the consequences of what's happening behind that. (Interview,
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45 002, female, 22, Site A)
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49 I think sometimes if you find it hard like to do something... like with my blood sugar
50 readings they've always been a problem and every clinic appointment it's the same
51 thing and the way its presented to me sometimes it's kind of like 'do you not get this
52 yet?' Sort of situation where you're just sort of sat there thinking I know exactly what
53 you're going to say, there's no point in saying it but you're going to say it to me
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60 anyway and I'm going to feel really bad about it and you're going to look at me with

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2
3 that expression on your face of 'are you an idiot?' Because you don't do it already.
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5 That's what it's like. (Interview, 004, 18, female, Site A)
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9 Interactions with the medical system imposed a set of expectations to optimise glucose
10 control. This conflicted with other central tenets of their adult transition; autonomy, choice
11 and independence. These values were constrained by a target driven medical culture,
12 concerned with outcomes and less with young people's personal and social challenges.
13 Clinicians' technical knowledge of diabetes control stands in contrast with young adults' lived
14 experiences. The consequence of life with diabetes is that targets must be met, and the
15 medical system is a constant reminder of 'disease' and 'difference'. Young adults did not
16 escape this reality. However, espoused resistance to the target driven medical system
17 offered some protection, helping to assert their independence as emerging adults able to
18 make their own decisions whether to follow targets. Such defiance might be viewed in terms
19 of an emergent 'resistance' narrative in contrast to the language of acceptance,
20 accommodation and stoicism reported in previous research on biographical disruption in the
21 context of old age (Pound 1998).
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39 There is clear indication of liminality at play. First, resistance to medically driven targets
40 enabled young adults to assert their independence. Clinic *appointments* and *targets* are a
41 disruption. Note, it is not simply the disease per se but the social relations around it that
42 cause disruption. Participants did not display resistance directly with clinicians in clinics, but
43 'quietly' in the way they attempted to live life as normal despite the medical advice. Living a
44 normal life as a young person outweighed the need to meet targets. These were not
45 completely disregarded, but glucose control was deprioritised in the context of socialising or
46 drinking alcohol. Acting as a normal young adult meant exercising choice and autonomy;
47 independence was the 'new' normality. Second, the clinical setting was perhaps easier to
48 negotiate than public space since young adults could ignore targets as these only became
49 relevant at specific times and relatively infrequently, hence at clinic appointments. For the
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3 large part targets were 'out of sight and out of mind'; they could be followed flexibly or not at
4
5 all. This created space for the resumption of normality and the 'backgrounding' of illness.
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7 Disruption moved in and out of view, manifesting during clinics and disappearing thereafter.
8
9 Disruption was liminal, though only occurred at certain time points, less frequently compared
10
11 to the disruption experienced in public spaces where young people spent most of their time.
12
13 Away from the clinic diabetes became a normal illness, 'ignored' or moved to the
14
15 background. They could after all depend on the safety net of the family as a last resort if the
16
17 condition got out of hand (Govey et al 2010).
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22 **'Daring to learn the complexity'**

23
24 A major difficulty of transitioning to adult life with type 1 diabetes was having the confidence
25
26 and courage to learn the complexity of disease self-management and letting go of the
27
28 dependency on parents to monitor glucose control. The WICKED course seemed to facilitate
29
30 such confidence. The adult transition is not a simple matter of a knowledge shift but also an
31
32 identity change, influenced by social and peer pressure, as well as balancing diabetes
33
34 control, school, and social life in a way that opens the way for future 'becoming' (Grosz
35
36 1999). The medical expectation to accomplish a radical shift in disease control was
37
38 countered by young adults' desire for tempered change to adjust to the complexity of living
39
40 with diabetes.
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45 We learned that you can't be perfect all the time you are going to have these ups and
46
47 downs and I think a lot of us its either got to be good or its got to be bad, they can't
48
49 be an in between (Interview, 005, female, 21 Site A)
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53 They sort of like taught us that it's normal to have blips and don't worry about it. As in
54
55 blips as in unlevel sugars. (FG, male, Site A)
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3 Young adults were taught to view glucose control as an imperfect task with inevitable
4
5 fluctuations. The disruptive elements of glucose control could in fact be viewed as 'normal'
6
7 after all. Others felt that diabetes was greater than the sum of its parts, again illness could be
8
9 accommodated into 'normal' everyday life. What seemed to matter was the totality of the
10
11 illness experience which was more significant than the individual elements of disease
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13 management.
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18 You can have like the tiniest little thing in your head, to somebody else even without
19
20 diabetes doesn't seem as big cos it's in your head sort of thing but when you've got
21
22 diabetes and you're high or you're low its bigger than your own head do you know
23
24 what I mean? It's gone out of the box. You're all over the place and everybody else
25
26 is just saying you've got to clean up that mess that you've caused and to be honest
27
28 you're not in the right state of mind to be touching any of that yet. Do you know what I
29
30 mean? And they try to push you towards it and people need to understand that it is
31
32 pressure. A hell of a lot of pressure on all of us. (FG, female, Site A)
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37 Here treating diabetes as a 'normal illness' is viewed as inevitable. Acknowledging the
38
39 complexity of living with and managing diabetes seemed to be a critical point, which
40
41 signalled the beginning of a new phase, and one which the following participant stressed
42
43 had to be recognised by the medical system. The complexity meant that targets could not
44
45 always be followed.
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50 Life events. I feel like life events need to be discussed. Things like festivals. Things
51
52 like travelling. We're dealing with young people that are deciding what they want to
53
54 do with their lives and you don't really realise how much having this illness affects
55
56 you in say the workplace or wanting to go travelling. The health insurance, the...
57
58 every little thing. Like if I was a normal person I would be like I'm just off to France
59
60 for the weekend whatever like I'm just going to book the flights and go. You have no

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2
3 idea that you've got to like... nobody takes actually on board that oh crap I've got to
4 take insulin, oh better get health insurance because you never really know what's
5 going to happen. (Interview, 003, female 21, Site A)
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11 The transition to life as an adult with diabetes seemed to require not only awareness of
12 diabetes management but a recognition of its complexity in the context of young adulthood.
13 The complexity was shaped both by the need for technical knowledge and tacit knowledge,
14 the latter was more about understanding each young adult's unique experiences and
15 personal responses to living and managing diabetes.
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24 Yeah. So my confidence has been built up from my just being confident with dealing
25 with diabetes day to day. (Interview, 005, male 21, Site A)
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30 Similarly, young adults valued listening to the experiences of their counterparts and the way
31 others managed their diabetes, helping to better understand their unique struggles.
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37 Just it opened, like other people's experiences opened my mind to like just a bigger
38 world I guess cos I've never really had problems with discrimination like a couple of
39 people in the course have and I've never really had problems with drinking and drugs
40 and things like that. So, it just made me realise that there are other things that could
41 influence me and that I could run into later on in life. (Interview, 007, female, 17, Site
42 A)
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51 If you've got the same sort of views you feel like something probably could be done
52 to change what we see as not right about social issues to do with diabetes and you
53 don't feel as alone really in terms of how you feel sometimes if you are the only one
54 that you know with diabetes you don't feel like you can do anything about it, you've
55 just got to accept it. Whereas now, meeting other people with diabetes that feel
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3 similar or the same way something could be done about it if we met with even more
4
5 diabetics not just the ones that attended the class (FG, female, Site B)
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10 The 'complexity' discussed here not only relates to the challenge of learning the clinical
11
12 knowledge for glucose control, but balancing this with everyday knowledge, activities and
13
14 distractions. The narratives stress the importance of acknowledging that living with, self-
15
16 managing and applying new learning about type 1 diabetes is difficult sense-making work
17
18 and not just a matter of telling yourself the simplified version ("eat your greens, inject your
19
20 insulin, all will be well and parents will watch over you"-authors' own words). In this way this
21
22 sense making work involves owning the knowledge rather than applying someone else's.
23
24 This is facilitated through the peer group of young people with diabetes. It needs to be their
25
26 knowledge, or knowledge which comes from their 'tribe' to have meaning. Facing up to the
27
28 complexity of diabetes self-management might be interpreted using a social capital
29
30 perspective (Bourdieu 1986). Knowledge acquisition must be turned into knowledge
31
32 ownership. 'Their knowledge' must become 'my knowledge', achieved through complex
33
34 sense making work and the active production of social capital (Helve and Bynner, 2007).
35
36 "Transition is not just what others do to us, but what we can do to help ourselves" (authors'
37
38 own words). In this vein they embodied clinical knowledge to make it their own, and in the
39
40 process moved gradually from biographical disruption to a life with a 'normal illness'. They
41
42 achieved this through self-reflection of how far diabetes could be readjusted to fit in with their
43
44 lives, not the other way around. The choice was no longer 'either' diabetes control 'or' living
45
46 life to the full as 'normal' (Babler and Strictland 2015). A compromise was reached and
47
48 suggests a movement from childhood dependency on 'others' to living independently with
49
50 complexity. Liminality in this context (compared to the public and clinical contexts) is
51
52 characteristic of a more radical shift towards a 'normal illness' narrative. Diabetes is still
53
54 disruptive, but it is 'foregrounded', brought into line with everyday routines.
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3 Disruption co-exists with life as 'normal'; one does not replace the other. One way of
4 conceptualising this theme is as 'narrative restitution'; the integration of technically complex
5 knowledge and an appreciation of the imperfect nature of type 1 diabetes self-management
6 within a new biographical narrative. Everyone is fallible and will get things wrong. Narrative
7 restitution is a work in progress for the young people in this study. It is however a key step in
8 the transition to a life as a young adult with diabetes (Babler and Strickland 2015).
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18 **Discussion**

19
20 Biographical disruption operated in three contexts; public spaces, clinics, and the knowledge
21 context (promoted by the WICKED study which helped to realign realistic expectations of
22 managing a complex illness). The implications of these findings are as follows. First,
23 'Nobody knows what it's like to be me' depicts the social pressures of living with, and
24 struggling against the cultural (mis) representations, of type 1 diabetes. This had profound
25 impact on our participants, leading to a mixed cocktail of feelings prompting a range of
26 responses. The most striking was hiding the condition by refusing to inject insulin in public
27 spaces, and perhaps putting themselves in danger. Frustration with others'
28 misunderstanding of type 1 diabetes and its aetiology was another common reaction. We
29 interpret these findings as the 'maintenance of a public self'. Disruption in this case requires
30 planning to minimise the risk of relapse at the 'wrong time' and illness exposure in public.
31
32 Second, 'It's me against the (medical) system' signified a desire by young adults for health
33 care provision to become more person-centred and less target driven. The clinic represented
34 dependency on medical systems, standing in conflict with young people's transition into
35 adulthood characterised by independence and autonomy. We can interpret this theme as the
36 desire to 'maintain an independent self'. Normality is only attainable if they can be
37 independent. It can be maintained in the face of clinical target disruption which our young
38 people were able to avoid or follow flexibly. Whenever not in clinic targets could be avoided
39 altogether if so desired. The disruption to self-described here is transient and temporary.
40
41 Third, 'Daring to learn the complexity', shows how young people step outside into the adult
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3 world navigating and comparing their experiences with those of others in their peer group
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5 (Reidy et al 2018; Kennedy et al 2016; Hempler 2016). Technical knowledge of diabetes
6
7 management only becomes relevant when it is 'owned'. The technical facts must be
8
9 transformed into practical wisdom to make sense and have long lasting application. The
10
11 argument we present is to show how young people's narratives represent a call for
12
13 'pragmatic' knowledge to facilitate the transition to a pre-illness identity. We coin this theme
14
15 'narrative restitution' (Frank 1995) where a shift occurs in illness disruption allowing for a
16
17 more realistic and practical understanding of disease self-management.
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22 Liminality in this context could be conceptualised as representing a dialectic relationship
23
24 between an *independent* and *pragmatic* self, perhaps located at opposite ends of the liminal
25
26 spectrum. Independence represents the desire to maintain autonomy in the face of
27
28 disruptive illness, by hiding the disease in public and resisting external interference from
29
30 those in authority. Disease is an interruption to living a normal life and an unwanted obstacle
31
32 to biographical continuity. This form of liminality is where disease is 'backgrounded' and the
33
34 quest for a normal life without illness is vigorously sought. Any talk of ill health is replaced
35
36 with talk of a future free of disease; it is removed from immediate view in the hope and belief
37
38 that it does not return. The converse appears to be the case in young adults adopting a
39
40 'pragmatic subject position'. Liminality in this case is characterised by the *foregrounding* of
41
42 disease in the hope that the pre-disease self can be reintroduced back into the new
43
44 biography. A process of 'restitution' is enacted involving biographical reconstruction and the
45
46 reintroduction of the former self into a new illness identity (Frank 1995).
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51 **Limitations**

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53 Although not statistically representative, the findings are likely to reflect experiences of the
54
55 broader population of young adults with Type 1 diabetes, although the aim was not to
56
57 generalize beyond the immediate study participants. The interview sample included 15
58
59 participants, which may be viewed as a low number, although we did reach 'data saturation'
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3 and did not require further data collection. In addition, the seven focus groups provided
4
5 further data which gave us confidence that we captured a broad range of views and
6
7 experiences in significant depth. As our participants were primarily white British, future
8
9 studies need to explore the views of a broader range of ethnic groups in search of possible
10
11 cultural differences in how young people navigate these three illness contexts.
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13

14 15 16 **Conclusion**

17
18 The findings have implications for health services. First, the pressure to maintain a normal
19
20 self in public requires greater recognition and guidance from health professionals (GPs and
21
22 diabetes specialists in secondary care) of young people's everyday challenges to self-
23
24 manage their diabetes. Particularly specific advice on how best to manage difficult or
25
26 embarrassing social situations *safely*. The struggle to lead life as normal despite the illness
27
28 is indicative of a need for practical guidance to negotiate challenging social situations.
29
30 Second, the adoption of an 'independent subject position' in relation to glucose targets
31
32 seems to suggest a need for a person-centred care model during clinic appointments,
33
34 responsive to young people's everyday struggles. This calls for more holistic healthcare
35
36 interactions which recognise the wider social context of glucose control. Finally, health
37
38 services need to deliver pragmatic education moving away from target driven approaches for
39
40 optimising glucose control; and towards a more flexible healthcare model to directly respond
41
42 to the often chaotic and uncertain experience of managing chronic illness during adult
43
44 transition. Research in educational settings has shown that young people are not only
45
46 passive recipients of capital from their parents, but creators of capital through their own peer
47
48 groups (Helve and Bynner, 2007). Peer groups, based on friendships created from
49
50 structured education programmes such as the one described in this paper, could facilitate
51
52 the formation of pragmatic self-management strategies through peer engagement and
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54 reflection.
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References

1
2
3 Allport, G. (1955) *Becoming: Basic Considerations for a Psychology of Personality*. Yale
4 University Press, New Haven, CT.
5
6
7
8

9 Arnett, J., 2000. Emerging adulthood: a theory of development from the late teens through
10 the 20s. *American Psychologist* 55 (5), 469–480.
11
12
13

14
15 Babler E, Strickland CJ. (2015) Normalizing: adolescent experiences living with type 1
16 diabetes. *Diabetes Education*, 41 (3), 351-60.
17
18
19

20
21
22 Balfe M (2007) Diets and discipline: the narratives of practice of university students with type
23 1 diabetes. *Sociology of Health and Illness*, 29 (1), 136-53.
24
25
26

27
28 Balfe, M. (2009) The body projects of university students with type 1 diabetes, *Qualitative*
29 *Health Research*, 19, 1, 128–39.
30
31
32

33
34 Barnard KD, Dyson P, Sinclair JMA, Lawton J, Anthony D, Cranston M, Holt RIG. (2014).
35 Alcohol and its impact on diabetes management. *Diabetic Medicine*, 31: 1625-1630.
36
37
38

39
40
41 Barnard KD, Lloyd CE, Dyson PA, et al. (2014). Kaleidoscope model of diabetes care: time
42 for a rethink? *Diabetic Medicine*, 31: 522-530.
43
44
45

46
47 Baron, S., Riddell, S., Wilson, A., (1999). The secret of eternal youth: identity, risk and
48 learning difficulties. *British Journal of Sociology of Education* 20 (4), 483–499.
49
50
51

52
53 Birt L, Poland F, Csipke E, G. Charlesworth G. (2017). Shifting dementia discourses from
54 deficit to active citizenship *Sociology of Health and Illness*, 39 (2) (2017), 199-211.
55
56
57
58
59
60

1
2
3 Blickem C, Kennedy A, Vassilev I, Morris R, Brooks H, Jariwala P. Linking people with
4 long-term health conditions to healthy community activities: development of patient-Led
5 assessment for network support (PLANS). *Health Expect.* 2013;16:e48-e59.
6
7
8
9

10
11 Brown B, Huszar K, Chapman R. (2017) 'Betwixt and between'; liminality in recovery stories
12 from people with myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS)
13
14
15
16 *Sociology of Health and Illness*, 39 (5), 696-710.
17
18
19

20 Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health & Illness*, 4, 2,
21 167–82.
22
23
24
25

26 Bury, M. (1988) Meaning at risk: the experience of arthritis. In Anderson, R. and Bury, M.
27 (eds) *Living with Chronic Illness. The Experience of Patients and their Families*. London:
28 Unwin Hyman.
29
30
31
32
33

34 Butcher, S., Wilton, R., 2008. Stuck in transition? Exploring the space of employment
35 training for youth with intellectual disability. *Geoforum* 39 (2), 1079–1092.
36
37
38
39
40

41 Carricaburu, D. and Pierret, J. (1995) From biographical disruption to biographical
42 reinforcement: the case of HIV-positive men, *Sociology of Health & Illness*, 17, 1, 65–88.
43
44
45
46

47 Coleman EA. *The Care Transitions Program*. Aurora, CO: Division of Health Care Policy and
48 Research, University of Colorado Denver [accessed 18-10-2017]
49
50
51
52

53 Dovey-Pearce, G, Doherty Y, May C (2007) The influence of diabetes upon adolescent and
54 young adult development: a qualitative study. *British Journal of Health Psychology*, 12 (1),
55 75-91.
56
57
58
59
60

1
2
3 Faircloth, C., Boylstein, C., Rittman, M., Young, M.E., et al. (2004) Sudden illness and
4 biographical flow in narratives of stroke recovery, *Sociology of Health & Illness*, 26, 2, 242–
5
6
7 61.
8
9

10
11 Frank, A. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago, IL: University
12
13 of Chicago Press.
14

15
16
17
18 Garvey KC, Beste MG, Luff D, Atakov-Castillo A, Wolpert HA, Ritholz. Experiences of health
19
20 care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolesc*
21
22 *Health Med Ther*. 2014;5:191–198.
23
24

25
26 Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*.
27
28 Stanford University Press: Stanford, California.
29

30
31
32 Goffman, Erving. *The Presentation of Self in Everyday Life*. New York: Anchor Books, 1959.
33
34

35
36
37 Grosz, E., 1999. *Becomings: Explorations in Time, Memory and Futures*. Cornell University
38
39 Press, Ithaca.
40
41

42
43 Harrison S, Stadler M, Ismail K, Amiel S, Herrmann-Werner A. Are patients with diabetes
44
45 mellitus satisfied with technologies used to assist with diabetes management and coping?: a
46
47 structured review. *Diabetes Technol Ther*. 2014;16:771-783.
48
49

50
51 Helve H, Bynner JM. (2007) *Youth and Social Capital*. London: Tufnell Press.
52
53

54
55
56 Hempler NF, Joensen LE, Willaing I. Relationship between social network, social support
57
58 and health behaviour in people with type 1 and type 2 diabetes: cross-sectional
59
60 studies. *BMC Public Health*. 2016;16:198.

1
2
3
4
5 Holland, J., Reynolds, T., Weller, S., 2007. Transitions, networks and communities: the
6 significance of social capital in the lives of children and young people. *Journal of Youth*
7
8
9 *Studies* 10 (1), 97–116.
10

11
12
13 Hopkins, P.E., 2006. Youth transitions and going to university: the perceptions of students
14 attending a geography summer school access programme. *Area* 38 (3), 240–247.
15
16
17

18
19
20 Hörschelmann, K., Schäfer, N., 2007. 'Berlin is not a foreign country, stupid!'— growing up
21 'global' in Eastern Germany. *Environment and Planning A* 39 (8), 1855–1872.
22
23
24

25
26 Hatton DL, Canam C, Thorne S & Hughes AM (1995) Parents perceptions of caring for an
27 infant or toddler with diabetes. *Journal of Advanced Nursing* 26, 259–577.
28
29
30

31
32 Horton, J., Kraftl, P., 2006a. Not just growing up, but going on: materials, spacings, bodies,
33 situations. *Children's Geographies* 4 (3), 259–276.
34
35
36

37
38
39 Jeffrey, C., Dyson, J., 2008. *Telling Young Lives: Portraits of Global Youth*. Temple
40 University Press, Philadelphia, PA.
41
42
43

44
45 Kennedy A, Vassilev I, James E, Rogers A. Implementing a social network intervention
46 designed to enhance and diversify support for people with long-term conditions. A qualitative
47 study. *Implement Sci.* 2016;11:27.
48
49
50

51
52
53 Knight K, Badamgarav E, Henning JM, Hasselblad V, Gano AD Jr, Ofman JJ, Weingarten
54 SR. A systematic review of diabetes disease management programs. *American Journal of*
55
56
57
58 *Managed Care*. 2005 Apr;11(4):242-50.
59
60

1
2
3 Larsson, AT., Grassman EJ. (2012) Bodily changes among people living with physical
4 impairments and chronic illnesses: Biographical disruption or normal illness? *Sociology of*
5 *Health and Illness*, 34 (8), 1156-69.
6
7
8
9

10
11 Lawton J, Waugh N, Noyes C, Barnard K, Harden J, Bath L, Stephen J, Rankin D. (2015).
12 Improving communication and recall of information in paediatric diabetes consultations: a
13 qualitative study of parents' experiences and views. *BMC Pediatrics*, 15:67.
14
15
16
17
18

19
20 Lee, N., 2001. *Childhood and Society: Growing Up in an Age of Uncertainty*. Open University
21 Press, Maidenhead.
22
23
24
25

26 Lucia Rojas Smith, DrPH, MPH, Mahima Ashok, PhD, MS, Sydney Morss Dy, MD,
27 MSc, Roberta C Wines, MPH, and Stephanie Teixeira-Poit, MS. Contextual Frameworks for
28 Research on the Implementation of Complex System Interventions. *Methods Research*
29 *Reports*. RTI International–University of North Carolina at Chapel Hill Evidence-based
30 Practice Center. Rockville (MD): Agency for Healthcare Research and Quality (US); 2014
31 Mar. Report No.: 14-EHC014-EF
32
33
34
35
36
37
38
39
40

41 Marshall M, Carter B, Rose K. (2009) Living with type 1 diabetes: perceptions of children and
42 their parents. *Journal of Clinical Nursing*, 18: 1703–1710
43
44
45
46

47 McDowell, L., 2002. Transitions to work: masculine identities, youth inequality and labour
48 market. *Gender, Place and Culture* 9, 39–59.
49
50
51
52

53 Monaghan, L.F. and Gabe, J. (2015) Chronic illness as biographical contingency? Young
54 people's experiences of asthma, *Sociology of Health & Illness*, 37, 8, 1236–53.
55
56
57
58
59
60

1
2
3 Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care:
4 internists' perspectives. *Pediatrics* 2009;123:417–423.
5
6
7

8
9 Pollock, G., 2002. Contingent identities: updating the transitional discourse. *Young* 10 (1),
10 59–72.
11
12
13

14
15 Pound, P., Gompertz, P. and Ebrahim, E. (1998) Illness in the context of older age: the case
16 of stroke, *Sociology of Health & Illness*, 20, 4, 489–506.
17
18
19

20
21 Putnam, 2000. *Bowling Alone: The Collapse and Revival of American Community*. Simon &
22 Schuster, New York.
23
24
25

26
27 Rankin D, Elliott J, Heller S, Amiel S, Rogers H, DeZoysa N, Lawton J. (2014). Experiences
28 of hypoglycaemia unawareness amongst people with Type 1 diabetes: a qualitative
29 investigation. *Chronic Illness*, 10 (3): 180-191.
30
31
32
33

34
35 Rankin D, Heller S, Lawton J. (2011). Understanding information and education gaps among
36 people with type 1 diabetes: a qualitative investigation. *Patient Education and Counselling*,
37 83: 87-91.
38
39
40
41
42

43
44 Reidy C, Bracher M, Foster C, Vassilev I, Rogers A. (2018) The process of incorporating
45 insulin pumps into the everyday lives of people with Type 1 diabetes: A critical interpretive
46 synthesis. *Health Expectations*, 21 (4), 714-29.
47
48
49
50

51
52 Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider
53 perspectives. *Pediatrics* 2005;115:112–120.
54
55
56
57
58
59
60

1
2
3 Sanders, C., Donovan, J. and Dieppe, P. (2002) The significance and consequences of
4 having painful and disabled joints in older age: co-existing accounts of normal and disrupted
5 biographies, *Sociology of Health & Illness*, 24, 2, 227–53.
6
7
8
9

10
11 Sanders T, Elliott J, Norman P, Johnson B, Heller S. (2018). Experiences of self-
12 management among young adults with Type 1 diabetes in the context of a structured
13 education programme: a qualitative study. *Diabetic Medicine*, 35, 1531-1537.
14
15
16
17
18

19
20 Sanderson, T., Calnan, M., Morris, M., Richards, P., et al. (2011) Shifting normalities:
21 interactions of changing conceptions of a normal life and the normalisation of symptoms in
22 rheumatoid arthritis, *Sociology of Health & Illness*, 33, 4, 618–33.
23
24
25
26
27

28
29 Saunders B, Bartlam B, Artus M, Konstantinou K. (2017) Biographical suspension and
30 liminality of self in accounts of severe sciatica. *Social Science and Medicine*, 218, 28-36.
31
32
33

34
35 Saunders B. (2018) 'It seems like you're going around in circles': recurrent biographical
36 disruption constructed through the past, present and anticipated future in the narratives of
37 young adults with inflammatory bowel disease. *Sociology of Health and Illness*, 39 (5), 726-
38 740.
39
40
41
42
43
44

45
46 Schur HV, Gamsu DS & Barley VM (1999) The young person's perspective on living and
47 coping diabetes. *Journal of Health Psychology* 4, 223–236.
48
49
50

51
52 Speight J, Amiel SA, Bradley C, Heller S, Oliver L, Roberts S, Rogers H, Taylor C,
53 Thompson G. (2010). Long term biomedical and psychosocial outcomes following DAFNE
54 (Dose Adjustment For Normal Eating) structured education to promote intensive insulin
55 therapy in adults with sub-optimally controlled Type 1 diabetes. *Diabetes Research and*
56
57
58
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62
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3
4
5 Strauss A. & Corbin J. (1994). Grounded theory methodology: an overview. In N. Denzin &
6 Y. Lincoln, Y (Ed), Handbook of Qualitative Research (pp. 273-285). California; Sage.
7
8
9

10
11 Trusson D, Pilnick A, Roy S. (2016). A new normal?: Women's experiences of biographical
12 disruption and liminality following treatment for early stage breast cancer Social Science and
13 Medicine, 151:121-129.
14
15
16
17
18

19
20 Valentine G. (2003). Boundary crossings: transitions from childhood to adulthood. Children's
21 Geographies, 1 (1): 37–52.
22
23
24
25

26 Williams, S.J. (2000) Chronic illness as biographical disruption or biographical disruption as
27 chronic illness? Reflections on a core concept, Sociology of Health & Illness, 22, 1, 40–67.
28
29
30

31
32 Wyn, J. & White, R. (1997), Rethinking Youth, Sage, London.
33
34
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36
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