

Title

“A confident parent breeds a confident child.” Understanding the experience and needs of parents whose children will transition from paediatric to adult care

Running head

Parenting during adolescent healthcare transition

Abstract

Transitional care for young people with long-term conditions emphasises the importance of supporting parents, particularly in relation to promoting adolescent healthcare autonomy. Yet little practical guidance is provided and transitional care remains suboptimal for many families. This study aimed to examine how parents understand and experience their care-giving role during their child’s transition to adult services, to identify parents’ needs and inform service improvements. Focus groups were undertaken with parents of young people with Brittle Asthma, Osteogenesis Imperfecta or Epilepsy. Data were analysed using Interpretative Phenomenological Analysis. Participants (n=13) described how their parenting roles extended beyond what they consider usual in adolescence. These roles were presented as time-consuming, stressful and unrelenting, but necessary to protect children from harm in the face of multiple risks and uncertainties. Such protective strategies were also perceived to hinder adolescent development, family functioning and their own development as mid-life adults. Finding a balance between protecting immediate health and long-term wellbeing was a major theme. Participants called for improved support, including improved service organisation. Recommendations are provided for working with parents and young people to manage the risks and uncertainties associated with their condition, as part of routine transitional care.

Key words

Parents, Transitional Care, Chronic Disease, Focus Groups

INTRODUCTION

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3 Transitional care for young people with long-term physical health conditions (LTCs) has gained
4 prominence over the last 20-years and is supported by a wealth of policies (e.g. American Academy
5 of Pediatrics et al. 2002; Kaufman et al. 2007), clinical guidance (e.g. National Institute for Health and
6 Care Excellence, 2016) and resources (e.g. Nagra et al. 2015; Trapeze, 2018). These acknowledge
7 that the transfer of young people from child to adult services is often poorly managed (Betz et al.
8 2015; Care Quality Commission, 2014; McManus et al. 2012) and associated with poor patient
9 outcomes (Lotstein et al. 2013; Yeung et al. 2008; Zhou et al. 2016).

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12 Improvement strategies increasingly highlight parents as important enablers in transition, helping
13 children to assume greater responsibility for their health and providing a protective factor in their
14 wellbeing (National Institute for Health and Care Excellence, 2016; Patton et al. 2016; Reed-Knight et
15 al. 2014). However, there is limited evidence to guide practitioners, including what constitutes
16 effective parenting in transition and how to support families as they realign their roles and
17 responsibilities. It is not surprising, therefore, that parents can feel unprepared for transition with
18 limited awareness of adult services and unable to anticipate their children's future needs (Betz et al.
19 2015; Heath et al. 2017).

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21
22 Transition can be a considerable source of parental stress, leading one review to conclude that more
23 evidence is "needed for the development of anticipatory guidance to assist parents as their children
24 transition into adulthood" (Betz et al. 2015 p. 402). This is in stark contrast to other areas of
25 adolescent health (e.g. sexual health, smoking) where the role of parents in promoting positive
26 outcomes is an important research focus (e.g. Kuntsche and Kuntsche, 2016; Wright and Fullerton,
27 2013).

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59 **AIM**
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3 To provide a detailed insight into how parents understand and experience their care-giving role
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5 during the transitional period, to identify their needs and inform service improvements.
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10 **METHODS**

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13 Data were collected using focus groups, selected for their interactive nature which fits well with the
14
15 social dimensions of parenting. The aim was to stimulate discussion between parents that would
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17 yield views and experiences of the parenting role throughout a child's healthcare transition. Focus
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19 groups were conducted within a framework of Interpretive Phenomenological Analysis (IPA) (Smith
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21 et al. 2009) designed for use in focus group studies (Palmer et al. 2010). This ensured interpretation
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23 of data took account of parents' individual 'lived experiences' while also identifying shared patterns
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25 of meaning across participants.
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30 **Sample and recruitment**

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32 To be included in the study, participants had to be a parent of a young person (aged 13-18 years)
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34 with Brittle Asthma (BA), Osteogenesis Imperfecta (OI) or Epilepsy (E), who was receiving care at a
35
36 large UK-based Children's Hospital. These disease groups were selected to represent a diverse range
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38 of LTCs affecting high volumes of patients, which have variation in age of diagnosis and require
39
40 varying degrees of parental/self-management, lifestyle modification and clinic attendance. All have
41
42 no cure and require management through self/parent-administration of pharmacologic or other
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44 treatments (e.g. physiotherapy). Parents whose children were already attending hospital-based,
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46 transition-related support groups were invited to participate by healthcare professionals known to
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48 them.
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57 **Data collection**

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3 Data were collected through disease-specific focus groups (BA, OI or E) following best practice
4 guidance (Kreuger and Casey, 2010). Focus groups were held at the Children's Hospital and designed
5 to run concurrently (but separately) to their children's support groups. Groups were facilitated by
6 two researchers who took steps to engender a permissive environment (i.e. non-clinical setting;
7 assurances of confidentiality; refreshments). Questions centred on: parent perceptions of their care-
8 giving roles during their child's transition to adulthood and adult services, impact of these roles,
9 unmet needs and support preferences. Probes were used to explore how participants
10 conceptualised the issues they faced, how they made decisions, and actions taken. Ethical approval
11 was granted by [committee name/ref removed for peer review]. Participants provided written
12 informed consent.
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26 **Data Analysis**

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29 Focus groups were recorded, transcribed verbatim, and anonymised. Analysis proceeded through an
30 eight-step IPA framework (Palmer et al. 2010) (Table 1). Coding was undertaken independently by all
31 authors using standard IPA practices, including (i) reflecting on personal beliefs and experiences, (ii)
32 repeated reading of transcripts, (ii) line-by-line coding, (iii) grouping of codes to generate themes
33 and (iv) interpretative work to understand how parents experience their care-giving role, and make
34 recommendations for transitional care (Smith et al. 2009). The research team met regularly to
35 discuss/refine ongoing analyses and to resolve any inconsistencies in coding or theme generation.
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46 [Insert Table 1 here]

48 **RESULTS**

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51 Thirteen parents from 10 families participated in focus group discussions, which lasted 90-120
52 minutes. Examination of positionality (Table 2) revealed that parents were positive about the
53 research aims and developed a rapid sense of togetherness, which was set against a backdrop of
54 physical and emotional isolation. Findings contained personal and revealing accounts, from which
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3 the researchers were able to discern themes that were meaningful in the context of parenting and
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5 transitional care.

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7 [Insert Table 2 here]
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10 **Protection**

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14 Linking all analytical steps, it was evident that *protection* was the issue of most concern. This was
15
16 considered an essential function of parenting, but described as difficult to achieve in the context of
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18 LTCs that posed significant threats to young people's lives. Participants described how their children
19
20 had experienced physical harms (including threats to life) as a consequence of their health
21
22 conditions, and used emotive language to indicate the 'traumatic' nature of these events or
23
24 quantifying details to convey ongoing risk (e.g. frequency, duration).
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28 *He's had about 45 fractures in the last 14 years. (OI)*

29
30 However, participants emphasized the importance of protecting young peoples' psychosocial
31
32 wellbeing, including emotional health, social functioning and academic attainment. Threats to future
33
34 well-being were also raised (e.g. vocation, relationships, discrimination):
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38 *...She's had three seizures so far, all happening at school, so it's had a big impact on her and her*
39 *social life in the school, in her general self-esteem – her self-belief is very, very low. (E)*

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41 *You know, in our society nobody offers marriages to girls with these things. (E)*

42
43 *My daughter's saying, 'I'm never having children because I don't want them to have epilepsy'. (E)*
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46 In light of this, parents described how their roles and decision-making were continuously shaped by
47
48 a need to protect their children. This included 'juggling' care commitments with other demands and
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50 persistent 'worry' and 'planning'. The unremitting nature of this was reinforced through use of
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52 temporal language ('everyday' 'every minute' 'every month', 'it just goes on and on and on') and list-
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54 like narratives:
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58 *Every single day you get up thinking is this going to be a good day, a bad day? Waiting for the*
59 *phone call from school saying she's had so many puffs on her inhaler she needs to go home.*
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3 *Planning days out, thinking how far do we need to be walking from one place to another? For us*
4 *it's whole life encompassing, everything is affected in one way or another. (BA)*
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8 Commensurate with their children's adolescent status, participants recognised that the protective
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10 functions previously handled by them needed to be transferred to young people to support their
11
12 'normal' development. This was demonstrated by parents emphasising the importance of letting
13
14 young people 'live their lives' and have 'freedom', as opposed to 'smothering', 'babying', 'holding-
15
16 back' or 'wrapping-them up in cotton wool'. Discussions centred on 'letting go' and handing over
17
18 'control' with most trying to adopt a balance of power that was neither too 'restrictive' nor too
19
20 permissive. This was usually described as a 'monitoring' role (e.g. supporting self-care, self-advocacy,
21
22 decision-making). It was also clear that role realignment was generally negotiated, with changes
23
24 instigated by parents and young people:
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28 *I remember when (My Son) was, I think he was 13. Up until that point I'd spent every night in*
29 *hospital with him and then he turned round and said 'why are you stopping [over]? Don't need*
30 *you anymore', so, I think for me that was probably the turning point. (OI)*
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33 However, 'letting go' was complex. Parents' desires to protect their children's long-term wellbeing
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35 (e.g. by fostering independence) were frequently at odds with their need to protect immediate
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37 health.
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40 *You know they need the independence but they're actually limited as well in what they can do...*
41 *So you wanna let them go but there's, it's diff, 'cos there's a balance between being safe and*
42 *being independent and that's a really hard one. (OI)*
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46 This appeared particularly true for those in the Epilepsy and Asthma groups, where symptoms could
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48 be unpredictable and potentially life-threatening, and where seizures or breathlessness reduced
49
50 young people's abilities to access help or self-advocate. In these cases, parents maintained high
51
52 levels of vigilance, ready to reclaim an active role should the young person be at risk of harm.
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55 *She was meant to have a sleepover with friends at Christmas time, but because her asthma was*
56 *so bad, it was sort of like 'We'll pick you up at half ten, eleven o'clock', because we couldn't risk*
57 *her staying over. (BA)*
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3 However, parental strategies to protect children caused additional pressures for both parents
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5 and their children.
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8 *So we are going through a very stressful life because every day, every minute, we are looking*
9 *out for our daughter. 'What is going on?' 'You are okay, you are okay?' ...and she is very*
10 *aggressive, especially because we are watching all the time. (E)*
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13 There was also a perception that young people were 'a little behind' compared to peers and had
14
15 fewer opportunities to develop and practice self-care skills.
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18 *You're trying to teach them all these skills that they've missed out on... especially social skills*
19 *because they've been cut off a lot socially or mixed with a lot of adults through hospitals. (OI)*
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23 In contrast, when the risk of harm was perceived to diminish, parents felt more confident to
24
25 promote independence. A consequence of this was increased opportunities for parental
26
27 development, as illustrated in the OI group where mothers had re-entered education or
28
29 employment. However, these choices continued to be shaped by the need to protect their children.
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32 *As they move into adolescence because their condition, either it's more stable or they're less, they*
33 *need you less because, you know, they're more independent... you've got the energy to then focus*
34 *on other things. So I set up my own business... but it's a totally flexible career so if I had to drop*
35 *everything, you know, tomorrow, I could literally be at the hospital in five minutes. (OI)*
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38 39 **Advocacy and care co-ordination** 40

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42 While participants valued the expertise and dedication of their healthcare teams, services were
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44 perceived as complex, confusing and fragmented. Words such as 'luck', 'chance' and 'word of
45
46 mouth' were used to describe how they had 'found' their way to specialist care. Services were also
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48 seen as process-focused, demonstrated through metaphors of being a 'number' rather than a
49
50 'person', on a 'conveyer belt', going through a 'sausage machine' and fitting into 'jelly moulds'.
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52 Parents felt frustrated by lack of consistency in personnel and joined-up working between hospitals,
53
54 primary care and schools.
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58 *The computers are not linked. That made me so angry. My daughter is actually sitting there and*
59 *your computers don't link. Seriously, what year are we, 1902? Your computers don't link? (E)*
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Poor awareness of the child's condition among health and education providers was a further source of concern. Participants felt this placed their children at risk (due to inappropriate or delayed care), and also served to marginalise them.

Attempts to protect young people from inadequacies in care meant participants frequently struggled with health and education systems. Frustration was evident in their use of 'conflict' metaphors (e.g. 'you've got to fight', 'battle', 'put your foot down, 'stand your ground'). To compensate, parents employed 'proactive' strategies, including the compilation of hand-held records (e.g. documenting children's medical histories and service involvement) and evidence of symptoms (e.g. video recording seizures).

We made sure we were involved... We had every letter that was ever written, everything that was ever said; I wrote down every seizure [our Son] ever had... I bought a special bag for it in the end.
(E)

Ostensibly, this was to facilitate continuity of care. However, documentary evidence was also used to reinforce credibility of parental concerns and act as a catalyst for action. It was felt that professionals did not always appreciate (believe or prioritise) the gravity of parental concerns. Yet collaboration with professionals was seen as pivotal to minimising risk. Parents valued staff who supported continuity of care across different parts of the system, describing them as 'marvellous' and 'gods'. However, their language emphasised these relationships as exceptional rather than normal.

Parents were particularly anxious about the impact of transfer to adult services on the quality of care received and unsure about transitional arrangements for their children. Preferences were for young people to transfer at a physically and emotionally 'stable' time, into 'developmentally appropriate' young-adult services that addressed all aspects of wellbeing.

These things are not just temperature or blood pressure. It's related to a human being, a future. We want, together, to make a good human being to participate in her life in a reasonable way.
(E)

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3 *[They're] going through all these emotions – the worst time in their lives and you're going to*
4 *hand them over to somebody different. (BA)*

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6 *It's almost like you need a 16 to 24 service because they're not really adults [no]; (E)*
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9 While parents had begun to hand over responsibilities for routine tasks to their adolescent children
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11 (e.g. medication, physiotherapy, family chores), they found it difficult to transfer responsibilities for
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13 co-ordination of care or clinical decision-making.
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16 *If they go to, say, you know, college, university and they're not at home, you'd have to make*
17 *connections with that hospital, and they have to then make decisions themselves, which I think is very*
18 *daunting for them and for us because we're the ones who always end up in the ambulance or at the*
19 *hospital with them, and they're gonna have to be doing things for themselves... that's a huge step,*
20 *isn't it? It's massive really. (OI)*
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23 Parents therefore remained a key advocate for their child and were concerned about children's
24
25 ability to cope unaided. Most were actively seeking opportunities for children to develop, practice
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27 and demonstrate self-care skills (e.g. on sleep-overs, school trips), but within safe environments
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29 where responsibility could be transferred to a 'trusted' adult. This in turn supported parents to 'let
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31 go' and also consider their own needs. However, they were rare occasions:
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35 *It was only because we knew him and we knew he understood what [our child's] condition was*
36 *[that we let her go on tour with choir] ...I think if you've got that trust in that person that's with*
37 *them then you're fine (BA)*
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39 *It's beneficial to us as well because you have at least some time where you can sit back, put a*
40 *movie on, go to a gig whatever, you can actually unwind yourselves... (BA)*
41

42 *I wouldn't have thought she'd be able to do that [deal with an attack by going to first aider]. I*
43 *think we sort of had to let her go and do it and when she came back she was a lot more confident.*
44 *(BA)*
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46 Participants called for increased emotional support for all family members. They valued the support
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48 groups their children were attending, but felt this should be extended to siblings and themselves.
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51 *My wife has started depression tablets. She's now taking tablets, so it's not only the child. These*
52 *things affect all your family. My wife is not in the position to talk to you. In two minutes she's*
53 *crying. (E)*
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55 They felt it was important to recognise that young people's outcomes were inherently linked to their
56
57 own capacity to support them, and described how adolescence brought new parenting challenges.
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3 *A confident parent breeds a confident child (E)*

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6 *As she's become older the parenting has become more difficult because it is just that whole stress of*
7 *what's going on when I'm not there. (BA)*

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10 Peer support was advocated as an important and credible mechanism to improve families' lives,
11 reflected in the focus groups which appeared to have a 'therapeutic' function for participants.

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15 *I would like to have that support for parents, like this one is, where the parent can come and meet*
16 *other parents who are going through the same process, as opposed to, 'Try this website and try*
17 *this website.' That doesn't help me, because when I want to talk, I don't want to go on a website*
18 *and read. I want to be able to say, 'This is how I'm feeling.' (E)*

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21 **DISCUSSION**

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24 The aim of this study was to explore how parents understand and experience their care-giving role
25 during the transitional period, to identify parents' needs and inform service improvements. Findings
26 revealed that parents perceived their role to extend beyond what they consider usual in
27 adolescence. This is consistent with previous literature outlining the concept of 'intense parenting'
28 (Woodgate et al. 2015) in which parents of children with complex care needs make commitments
29 that go beyond 'normal parenting' and extend longer into adolescence. Participants in the present
30 study described a similar range of roles, characterised by the previous authors as encompassing the
31 skills of a 'health care provider', 'case-manager', 'student', 'educator', 'detective', 'guard', and
32 'advocator'. What this study adds, however, is increased understanding about how participants
33 arrived at these intense and extended parenting roles.

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Using IPA in a group setting revealed that individual's narratives were underpinned by a shared need
to protect children from harm, with parental behaviour shaped by appraisals of children's
vulnerability, risk and uncertainty. Specifically, it showed parents working hard to help children
master developmentally appropriate skills, but unwilling to 'let go' when risks to health were high or
uncertain. This chimes with existing theories suggesting that while parents are driven to protect
young people's "physical, psychological, spiritual, ethnic and cultural integrity", their parenting

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3 functions are arranged hierarchically with children's survival/health preceding all other goals (Small
4 and Eastman, 1991, p. 456). The increasing maturity of adolescents usually means they are less
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6 dependent on their parents to keep them safe, instigating a parental shift towards protecting
7
8 through monitoring, teaching self-care skills, guidance and advocacy (Small and Eastman, 1991).
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11 However, parents who perceive their children to be at risk of harm will find it harder to adopt 'hands
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13 off' protective strategies. This explains observations that parental involvement in managing young
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15 people's LTCs does not decrease as much as would be expected in adolescence, and that parents can
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17 provide a protective health factor during transition (e.g. better glycaemia control in diabetes)
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19 (Duncan et al. 2014; Reed-Knight et al. 2014; Wiebe et al. 2014). However, while this may provide
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21 protection in high risk situations, excess parental concern and over-protection in low risk
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23 environments may negatively affect adolescent development (Small and Eastman, 1991; Woodgate
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25 et al. 2015). This was recognised by participants themselves, who called for greater support to
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27 manage protective tensions.
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33 Parental involvement in transitional care has been described as a source of tension for health
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35 professionals who empathise with parents' wishes to remain involved in children's care, but consider
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37 'over involvement' a barrier to effective transitional care (e.g. Iles and Lowton, 2010; Shaw et al.
38
39 2004). Disagreements between young people and parents in their views of and approach to young
40
41 person autonomy have also been reported (Peeters et al. 2014). Our study suggests that parents'
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43 intense and extended roles in adolescence may be better viewed as natural responses to real and
44
45 anticipated threats of harm. From this stance, helping families to cope with risk and uncertainty
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47 seems a necessary component of effective transitional care. This is consistent with evidence that
48
49 illness-related uncertainty not only impacts on parental distress and children's outcomes (Carpentier
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51 et al. 2006; Chaney et al. 2016), but is mediated by parents' appraisal of their caregiving demands
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53 (Chaney et al. 2016). For example, parents with higher levels of uncertainty may engage in more
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55 protective activities; these additional demands may subsequently increase parenting distress, which
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57 in turn may reduce capacity to promote children's well-being. The need for intervention is reinforced
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3 by Hinton and Kirk (2016) who found parents' attempts to manage illness-related uncertainties can
4 actually exacerbate uncertainty, diminish hope or cause distress. This was evident in our study (e.g.
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6 constant monitoring highlighted symptoms and signs that parents did not know how to respond to,
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8 which caused personal anxiety and negative reactions from children who were frustrated by
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10 parental surveillance).
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15 Findings also suggest that perceptions of risk, uncertainty and vulnerability can vary by condition.

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17 The concept of condition-related stigma for example, was described by parents in the epilepsy group
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19 as a potential risk to young person well-being, but less so by parents in the non-neurological
20
21 condition groups. The experience and impact of stigma has been long-recognised in epilepsy
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23 research, including literature related to young people (MacLeod and Austin, 2003). It is likely that
24
25 interventions targeting perceptions of 'difference' (Lambert and Keogh, 2015) would be of benefit
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27 across conditions as parents in all groups described challenges with helping their children to develop
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29 a positive sense of self, highlighted by how young people's attempts to 'fit-in' (e.g. through non-
30
31 disclosure, non-compliance with medication) incurred additional risks for their health. Participants
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33 in the Osteogenesis Imperfecta group described the risks of harm as diminishing in adolescence,
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35 which allowed them to reduce their parenting commitments and pursue personal goals (e.g.
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37 vocational retraining, increased social life). In contrast, parents in the Epilepsy and Brittle Asthma
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39 groups felt that reduced parental involvement could increase young people's vulnerability, given
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41 their children were unable to advocate for themselves in the event of a seizure or attack. Similar
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43 differences have also been reported by Hullmann et al. (2010) in a study of 425 parents whose
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45 children had asthma, diabetes, cancer, and cystic fibrosis. They concluded that parents perceptions
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47 of increased vulnerability is related to the unpredictability of symptoms and potential for premature
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49 death, whereas increased stress is a function of daily treatment demands. What this study adds, is
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51 evidence that increased perceptions of adolescent vulnerability and risk can impact negatively on
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53 young people's transitional readiness and parent's development as mid-life adults.
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Implications for practice

While communication about risk and uncertainty is a cornerstone of clinical practice, it can be challenging for health professionals (Alaszewski and Horlick-Jones, 2013) and tends to be narrowly focused on the probability of health outcomes, benefits and harms associated with tests and treatments, and lifestyle risk factors (Morden et al. 2012). The results of this study suggest that families would benefit from a more holistic approach that incorporates how young people and parents experience and understand risk, uncertainty and vulnerability. This echoes the views of Morden et al. (2012, 2015) who, in the context of adult chronic illness, discuss the “dissonance between the prevailing clinical perspective of risk, [and] the risks people encounter in their daily lives” (2015, p. 888) and suggest that understanding ‘lay’ constructions and enactment of risk is central to supporting self-management (2012). A potentially useful taxonomy has been developed by Han et al. (2011) to help professionals working with families to develop a ‘shared consciousness of uncertainty’, thereby identifying goals and strategies to support them. This organises uncertainties by *issue* (i.e. whether it is a clinical, practical or personal concern), *source* (i.e. whether it emanates from issues around probability, ambiguity or complexity) and *locus* (whether it resides in the minds of patients, parents or professionals). However, while some uncertainties may be reducible (e.g. through improving understanding), it is likely that many are not, or may not be warranted (e.g. individuals may choose to live with uncertainty about prognosis to preserve hope). Instead, families will need support to develop coping strategies that are informed by uncertainty, rather than based on anxiety (Han et al. 2011).

Parental interventions to reduce uncertainty are limited, but preliminary evidence suggests they can be effective (Fedele et al. 2013; Hoff et al. 2005). A 12-week in-clinic intervention delivered by psychology and nursing professionals was reported to have benefits for maternal distress, posttraumatic stress, caregiver burden and child internalising behaviours (Fedele et al. 2013). This included sessions on the nature of uncertainty, communication with medical staff, cognitive coping,

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3 problem-solving, social support, and consolidation of skills. A brief manualized intervention (2 x 2.5-
4 hour group sessions) designed to decrease uncertainty and distress in parents of children with newly
5 diagnosed diabetes (Hoff et al. 2005), also reported significant reductions in psychological distress
6 for both Mothers and Fathers, despite levels of perceived uncertainty remaining unchanged. These
7 findings suggest that equipping families with techniques to manage uncertainty (e.g. problem-
8 solving, communication skills, role clarification) may be more important than teaching them to
9 reduce uncertainty itself. Further intervention studies using frameworks such as Uncertainty in
10 Illness Theory (Mishel, 2002) are needed to build the evidence-base regarding how best to support
11 parents, in processing and managing illness-related uncertainty.
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24 Reducing uncertainty also requires wider changes. While parents valued the expertise and
25 dedication of their healthcare teams; uncertainty and risk were linked to poor service organisation
26 and delivery. Of note, is that parents' suggestions for improved care (i.e. care that is consistent,
27 developmentally appropriate, holistic, individually tailored and based on anticipatory collaborative
28 planning) echoes the central tenets of person-centred care (WHO, 2007) and transitional guidance
29 (e.g. National Institute for Health and Care Excellence, 2016). While reflected in healthcare policies,
30 these aspects of care were not translated into practice for these parents. In part, this may reflect
31 'embedded controversies' about whether developmentally appropriate healthcare should be
32 integral to adolescent services or an adjunct to the medical components of care (Farre et al. 2014).
33 Nevertheless, transition is described as posing additional risks and uncertainties that are uniquely
34 related to shifts in young people's biopsychosocial development, their responsibilities for self-care
35 and care provision. Research examining transition readiness indicates that premature transfer of
36 responsibility can be harmful for young people, and is best achieved through high quality
37 relationships where parental involvement shifts in relation to the adolescent's growing self-efficacy
38 (Van Staa et al. 2011; Wiebe et al. 2014). Building on these studies, the present findings suggest a
39 number of ways that health professionals could work collaboratively with families to support
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3 transition (Table 3). This includes strategies to help parents protect their children in developmentally
4 appropriate ways, thereby promoting the personal growth of young people and parents.
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8 This study is not without limitations. Participants were recruited from one UK hospital, and the
9 sample size was small, although consistent with an IPA approach. In addition, most young people
10 were in early adolescence. It is acknowledged that parental concerns may change over time, leading
11 to potentially different concerns at the time of transfer to adult services to those reported in this
12 study. Nevertheless, transition is argued to start long before transfer. Understanding parental
13 concerns early on in the transition process may support more timely interventions that mitigate later
14 issues. This said, ensuring developmentally appropriate care will undoubtedly require regular
15 assessment of adolescent and parental need, as they face new challenges together (Farre et al.
16 2014). Another potential caveat is that the results may not reflect the experiences of other parents.
17 Thus, while the findings contained many revealing accounts and generated shared themes, the
18 recommendations must be taken with caution. However, the findings were consistent with other
19 literatures and it is hoped that key themes of risk and uncertainty may provide alternative ways to
20 frame transitional care, using language and concepts familiar to all professionals.
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38 [Insert Table 3 here]
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41 **CONCLUSION**

42 In this paper, we reported findings of a qualitative study of parents' experiences and needs during
43 their child's transition to adulthood and adult healthcare services. This is important because parents
44 play a vital role in transitional care, including supporting young people to become independent and
45 effective health service users. Our findings suggest that parent narratives are underpinned by a
46 shared need to protect children from harm, with parental behaviour shaped by appraisals of
47 children's vulnerability, risk and uncertainty. We recommend professionals work with parents and
48 young people to develop anticipatory plans to manage such risk and uncertainty, and that this
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3 become a part of routine transitional care. We offer practical suggestions for doing so, based on
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5 existing policy and guidance.
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3 **Table 1. Summary of analytical steps**
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5 **Analytical steps (based on Palmer *et al.* 2010)**
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8 **1. Objects of concern and experiential claims of the individual participants**

9 Line by line coding (staying close to participant's own language) to identify what is important to participants,
10 exploring claims made about these objects of concern, examining meaning, and noting potential emergent
11 themes.
12

13 **2. Positionality**

14 Examination of the roles played by the facilitators and participants in the group and influence of their stances,
15 perspectives, and characteristics on the data and the process by which it emerges.
16

17 **3. Roles and relationships**

18 Examination of the roles and relationships described by participants, the meanings and expectations attributed to
19 these relationships, and the consequences of these.
20

21 **4. Organisations and systems**

22 Examination of the organisations and systems described by participants, the meanings and expectations attributed
23 to these, and the consequences of these.
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25 **5. Stories**

26 Examination of the role of narratives within the group i.e. how and why participants tell stories. Involves
27 examination of structure, genre, imagery, tone temporal references, and how participants impede/share
28 narratives.
29

30 **6. Language**

31 Examination of language used in steps 1-5 and how it maps to emergent themes, including participants' uses of
32 metaphor, euphemism, idioms, patterns of language use, context and function.
33

34 **7. Adaption of the emergent themes**

35 Adaption of the emergent themes in stage 1 in light of the subsequent steps, examining the patterns and
36 variations in experiences shared in each group (e.g. areas of consensus, conflict, marginalised views).
37

38 **8. Integration**

39 Examination of commonalities and differences between the groups to refine interpretations and examination of
40 these in the wider context of existing literature and theory to form an overall analysis of the topic.
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Table 2. Participant characteristics and positionality

		Brittle Asthma	Osteogenesis Imperfecta	Epilepsy
Parent	Mothers	2	3	3
	Fathers	2		3
	Age (range)	42-53 years	40-47 years	41-49 years
	Employment	Full-time: 3 Home-maker: 1	Full-time: 2 Self-employed: 1	Full-time: 4 Part-time: 1 Self-employed: 1
	Marital status	Married: 4	Married: 2 Divorced: 1	Married: 6
Patient	Son		3	3
	Daughter	3		1
	Age (range)	13-14 years	14-18 years	13-16 years
	Age diagnosis (range)	2-3 years	2 days – 2 years	6 months – 13 years
	Daily activities affected	All activities: 1 Most activities: 1 Some activities: 1	Most activities: 1 Some activities: 2	Most activities: 1 Some activities: 2 No activities: 1
	Hospital admissions in last 6-months (range)	Planned: 1-13 Unplanned: 0-8	Planned: 2-9 Unplanned: 0-1	Planned: 2-12 Unplanned: 0-3
	Siblings (range)	1-5	1	1-2

Analysis of Positionality

Participants: Positive about research aims (i.e. perceive a need for the study, hopeful for change and high level of engagement); Supportive (actively supporting one another to share experiences, set own narratives in context of each other's experiences, offering empathy and advice); Seeking social connection (high level of interaction, self-disclosure, affirming one another's similarities, seeking validation of their own thoughts and validating the views of others); Respectful of differences (in experiences, values and cultural positions); Broadly critical of services, (expressed frustration and conflict with services) although highlight examples of good practice and supportive individuals; Highlight therapeutic role of focus group (parents offered empathy and exchanged information/parenting advice; parents viewed as sincere and credible sources of support because knowledge derived from lived experience; benefit of peer support set against a backdrop of social isolation due to care commitments and perception that others, including family members and health professionals, rarely appreciate the full impact of their situations).

Facilitators: Limited input sticking closely to topic guide and only occasional prompting and clarification required (as a consequence of positive participant engagement). Adopted a solution-focused stance, asking participants to consider how problems/challenges described in their group could be avoided/addressed, including preferences for potential solutions.

Table 3: Practical suggestions for supporting parents in transition**Implement transition plans**

Implement developmentally appropriate care that capitalises on each family's strengths and capabilities. While the rights of young people are paramount (e.g. right to be seen alone, confidentiality), the enabling roles of parents should be acknowledged and supported as part of a partnership approach. Resources are available to guide the development of youth friendly services, including frameworks to assess and plan transitional care for young people and their parents (e.g. Nagra *et al.* 2015, Trapeze, 2018).

Identify and address concerns about risk and uncertainty

Provide space and time for families to raise concerns about vulnerability, risk and uncertainty. Existing frameworks (e.g. Han *et al.* 2011) may help different types of uncertainty to be explored. Work collaboratively to prioritise concerns and make anticipatory plans to manage them. This may involve addressing uncertainties related to the young person's condition, generic adolescent health and wellbeing issues, role of parents in transition, and the organisation of services.

Minimize Child Vulnerability

Transition readiness (self-efficacy) is an important predictor of successful transition to adult healthcare (Van Staa *et al.* 2011; Wiebe *et al.* 2014). Transfer of responsibility should therefore be part of a planned approach in which parental involvement reduces incrementally in response to the young person's increasing capabilities. This can be promoted by:

- Assessing young people's competence and confidence in relation to key transitional goals.
- Helping parents to remain involved in young people's care in ways that foster transition readiness.
- Providing young people with 'safe' opportunities to experience manageable levels of risk and responsibility and develop self-management skills. This should be demonstrable to parents to minimise perceptions of child vulnerability. Healthcare providers could encourage self-advocacy in clinics, offer skills workshops, signpost wider opportunities (e.g. those offered by charities/youth organisations), and encourage families to create opportunities at home for their children to learn and practice self-care skills.

Support parenting capacity

Emphasise to parents, the importance of empowering young people to protect themselves. This may include discussions about young people's rights as patients, their increasing needs for autonomy, expectations about self-management and service use in adulthood. Information to help parents identify common adolescent problems (e.g. depression, eating disorders) may be useful. Parents may also benefit from help to develop effective monitoring skills that are appropriate to the young person's developmental stage, and support with managing family dynamics (e.g. referral to counselling to support communication, conflict resolution, positive role modelling etc). Develop community-based parenting programmes that are culturally sensitive and relevant.

Support family wellbeing

Acknowledge the developmental changes of mid-life adults and how this affects parenting roles and relationships with children. Facilitate coping skills relevant to transition stressors (e.g. extended parenting roles, diminished caring role, loss of control). Psychosocial support may be useful where there are unavoidable risks and high care demands. Provide opportunities for young people, parents and siblings to meet others in a similar situation (e.g. peer support groups, social media groups, peer-led education, buddying). 'Family Facilitators' (i.e. parents with 'expert' knowledgeable about transition) and transition support groups have been shown to be helpful for some parents (Kingsnorth *et al.*, 2010).

Identify and address organisational barriers

Minimise sources of uncertainty by providing consistent care (seeing same healthcare team), joined up services

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(between hospitals and hospitals and schools), continuity at transfer, transfer at times of health stability. Self-assessment and benchmarking tools to support best practice are available (e.g. National Institute for Health and Care Excellence 2016; Aldiss *et al*, 2015). Support families to understand how services are organised, how to access them and strategies for healthcare use and help-seeking. Promote public understanding of LTCs in adolescence.

For Peer Review