

Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities

Abstract

Aims and objectives: To explore the experiences of the families of young adults with intellectual disabilities (ID) at the point of transition from child to adult health services.

Background: The population of people with ID is changing rapidly, with young people with increasingly complex needs surviving into adulthood and requiring transition from child to adult health services.

Design: An interpretative qualitative design.

Method: Semi-structured interviews were held with ten family carers of young adults with ID and complex care needs, who were in the process of or had recently completed a transition from child to adult health services in Scotland. Data was analysed using thematic analysis. The COREQ checklist was used.

Results: Transition emerged as a highly emotional and challenging period for family carers. Their experiences were captured in five main themes: “a deep sense of loss”, “an overwhelming process”, “parents making transitions happen”, “a shock to the adult health care system” and “the unbearable pressure”. Nurses were often seen as instrumental to counteracting some of these challenges.

Conclusion: There is an urgent need to respond to the challenges experienced by carers at the point of transition and beyond, by ensuring early and coordinated planning, effective information sharing and communication and clear transition processes and guidelines. A person-centred and family-centred approach is required to minimise negative impact on the health and wellbeing of the young adult with ID and their carers.

Relevance to clinical practice: Registered nurses have a key role in providing information and support, along with coordinating care at the time of transition from child to adult health services for young adults with complex ID. It is vital that their input is person-centred and responds effectively to the expert knowledge of family carers, whilst at the same time ensuring their needs for information and support are also addressed.

Key words: Intellectual disabilities, transition, complex needs, carers, nursing, qualitative research

What does this paper contribute to the wider global clinical community?

- Young adults with ID and complex needs and their family carers continue to experience multiple challenges at the point of transition to adult health care and beyond
- Carers' experiences highlight the areas of support that need addressed in order to ensure a more coordinated process and minimise the negative impact of transition on people with ID and their carers
- Registered nurses can play a key role in enabling person-centred and family-centred care at the point of transition and beyond

INTRODUCTION

There is an established body of research evidence regarding health transitions from child to adult health services for young people with a range of health conditions, including diabetes, epilepsy and cystic fibrosis (Sheehan et al., 2015; Camfield et al., 2017; Coyne et al., 2017). All point to this period presenting challenges for the individual and their families, as a result of biological, sociological and psychological changes for the young person as well as significant changes in the organisation of their care. Due to advances in medicine, the number of young adults with intellectual disability (ID) and complex health needs living into adulthood is increasing (Jarjour, 2015). As a result, they require specialist health care provision extending beyond child health services. For young people with complex needs planning for transition to adult health services is recommended to start around the age of 14 (NICE, 2016). However, evidence suggests that internationally the overall health transition process presents numerous challenges for people with ID and their carers (Brown et al., 2019). Given the central role that family carers play in the care of young people with complex ID, it is essential to understand their experiences of health transitions, to ensure that nurses and other professionals respond to their needs.

BACKGROUND

Health care transition is defined as “*a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems*” (Department of Health, 2006 p.14). Given the high prevalence of specific health conditions in people with ID, such as respiratory, gastro-intestinal and neurology conditions (Cooper et al., 2015), individuals and their families are likely to encounter a wide range of health services. Continuity of care can be disrupted during this period, which can result in problems with the management of existing conditions or a lack of detection of new conditions (Young-Southward et al., 2017a). This also extends to mental health needs, as Cvejic and Trollor (2018) highlight young adults with ID are at an increased risk of mental health disorders during the period of transition to adulthood.

Evidence from international studies indicates that carers often feel a sense of loss and abandonment during the transition from child to adult health services (Bhaumik et al.,

2011; Davies et al, 2011; Schultz 2013; Young-Sutherland et al., 2017b), with concerns that it may result in poorer health outcomes for the young person (Camfield et al., 2011; Woodward et al., 2012; Bindels-de Heus et al., 2013; Jensen & Davis 2013). A recent systematic review on transitions from child to adult health care for young adults with ID identified a theme of “*parents as advocates in emotional turmoil*” (Brown et al., 2019 p.11). Some parents described the need to ‘fight’ for effective health care following transition and achieving a successful outcome was often dependent on their own resourcefulness and persistence.

Meleis et al. (2000) developed a theory of nursing transitions that recognises the complexities of the concept, which occurs in a wide variety of health care contexts. Examples include age-related transitions such as moving from child to adult services, role-related issues, including adult children assuming responsibility for older parents, or location-related, such as moving from home to a care home. Meleis et al. (2000) identify three main elements within the theory: the nature of transitions, transition conditions and the patterns of response. Whatever the transition, it generally involves multifaceted systems, protocols and personnel. The health care elements can occur at critical points in people’s lives that are already characterised by anxiety and uncertainty. By developing an understanding of the experience of transition in the context of the theory by Meleis et al. (2000), nurses can more effectively influence transition planning and support for those involved.

This paper reports on one component of a Scotland-wide study to explore the transition from child to adult health care for young adults with complex ID from the perspective on nurses and family carers. The overall aims were to identify examples of good practice and to develop and pilot an educational resource on transitions for both child and adult nurses.

The objectives of this element of the study were to:

- 1) Explore the experiences of transition from child to adult health care from the perspective of family carers of people with ID and complex needs.
- 2) Investigate best practice, including the contributions of registered nurses experienced by family carers and individuals with ID and complex needs at the point of transition to adult health care.

- 3) Identify the support needs of young adults with ID and their carers at the point of transition from child to adult health services.

METHODS

Design

The wider study employed an interpretative qualitative design involving semi-structured interviews with family carers of young adults with ID (n=10), registered nurses (n=43) and other health professionals (n=3) across Scotland. The data presented in this paper is drawn from the interviews with family carers and analysed using thematic analysis (Braun and Clarke, 2006). The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007) were adhered to during the reporting of this study (See Supplementary File 1).

Recruitment and participants

A number of independent sector organisations and carer groups, such as the Scottish Consortium for Learning Disabilities (SCLD) and Promoting A More Inclusive Society (PAMIS) in all 14 National Health Service (NHS) Health Boards in Scotland provided support with recruiting family carers. Using purposive sampling, they shared a Participant Information Sheet with carers in their networks whom they deemed suitable for this study. Carers interested in participating were asked to contact the research assistant (AH), who fully briefed them about the purpose of this study and screened against the inclusion criteria. These included having a child with a complex ID and being in the process of or having recently completed a transition process from child to adult health services. In total, ten family carers from seven NHS Health Boards in Scotland were identified and agreed to participate. Table 1 gives details of demographic information for carers and young adults with ID. The young adults with ID had a range of diagnoses and comorbid health conditions, including epilepsy, visual impairment or blindness, musculoskeletal conditions, kidney and metabolic issues, gastrointestinal and respiratory problems, speech and language difficulties and mental health issues.

(Table 1 here)

Data collection

A semi-structured interview schedule (Box 1) was developed for the purpose of this study drawing on current literature and the expertise of the research team and the study Advisory Group. The group included representatives from carers, voluntary and professional organisations associated with people with ID and academia. The schedule was piloted with two carers and these interviews are included in the study results. Interviews ranged from 40 minutes to over one hour. They took place between November 2016-July 2018 and were conducted by the research assistant (AH), who is experienced at qualitative data collection. Based on participants' personal preference or travel distance, the one-to-one interviews were conducted in the participants' homes (n=5), workplace (n=1) or over the telephone (n=4). Data saturation was reached after eight interviews and two more interviews were conducted. All interviews were audio recorded and transcribed verbatim by a professional transcription service. The interviewer (AH) anonymised the transcripts and returned to participants for comments. All carers were ascribed a code number and pseudonyms were given to the young person with ID to preserve anonymity.

(Box 1 here)

Ethical considerations

The University Research Ethics and Governance Committee independently reviewed the study and granted approval, with all research ethics and governance procedures adhered to in each NHS Health Board.

Data analysis

Thematic analysis, inspired by the step-by-step guide by Braun and Clarke (2006) was employed to systematically identify recurring themes. Thematic analysis is used to identify, analyse and report patterns within data and can be extended to interpret various aspects of the research topic. This method is independent of epistemology and theory and can be applied flexibly to produce a rich and complex account of data (Braun and Clarke, 2006). The analysis was focused on describing and interpreting carers' experiences, attitudes and meanings related to the transition process.

The research assistant (AH) generated initial codes for individual transcripts and collated them into initial themes. These were then reviewed and refined into main themes and subthemes. QSR NVIVO 11 software was used to manage the data and support the systematic approach to analysis. To ensure rigour, the analysis was systematically discussed and reviewed by two other members of the research team (MB, JM). Additionally, findings were shared and reviewed by the study Advisory Group to support peer debriefing.

RESULTS

For most of the young adults in this study transition from child to adult services had commenced after the age of 14 and was complete by the age of 19, although for one individual transition had taken place between the ages of 24-26. Although one of the aims of the study was to identify positive examples of practice related to transition, the majority of experiences reported by parents were largely negative. This had a clear impact on their overall perception of transition, their own wellbeing and in some cases had a detrimental effect on their child's health and experience of care. Five themes with associated sub-themes were identified and are reported in Table 2.

(Table 2 here)

A deep sense of loss

Losing the sense of safety

Parents expressed feelings of deep trust towards their child health team, which provided them with a strong sense of safety. The introduction of the concept of transition to adult services was often sudden and unexpected and parents commonly viewed transition as a loss of the entire professional support network and relationships that had been built over many years:

There's very little emotional support for parents, and it's a very scary process where you feel...you feel you're going into a very vulnerable situation, to let go of a doctor that you deeply respect, like, there's real affection for each other and mutual respect for each other, and all of a sudden it's like somebody taking a rug and just pulling it out [C05].

Loss of integrated services

Parents expressed feelings of fear and anxiety about losing access to what they viewed as vital services and expertise, often provided by a single clinician and specialist nurses. Their concerns about the ability of adult services to meet their child's complex needs were driven by the move to a range of specialists and had often been reinforced by negative stories from other parents, who had already gone through transition:

I've heard these horror stories of parents being told, 'you're off paediatrics now, you're back to the GP', and of course the GP in our case doesn't know our son. All of a sudden, you've been a parent of a little lad, and this is a boy that had people at a major UK children's hospital, and you've had that level of expertise. [Now] you have a different person for the bones, you have a different person for the spine, you have a different person for the gastric, you have a different person for neurology, you have all these people. [C05]

A sense of isolation and vulnerability

This stressful time had a negative impact on parents who expressed feelings of isolation and being overwhelmed while continuing to deal with their child's highly complex needs. There was a sense that transition to adult services also meant a loss of emotional support from professionals who had known their family for many years:

[Children's Community Nurse] would drop off the supplies, but she would say, 'how's it going?' or whatever, so I'd see her approximately once a month, and she was always at the end of the phone. If I hadn't seen her every six months approximately, she would come and have a cup of tea and just chat how things are. (...) if you were admitted to hospital, she would know about it and she'd pop in to see you. [C07]

An overwhelming process

Re-establishing a care team

These parents described the process of establishing a new care team in the adult services as complex and confusing, with multiple meetings and what they felt was a 'minefield' of information:

(...) obviously, you have to move on at some point. So, then that involved more people, more information given, more meetings, things like that. [C01].

Parents reported a lack of continuity or information sharing between professionals and felt drained by having to continually repeat the same information to different health care teams:

(...) it's just the sheer fact that you almost have to start again with referrals in many cases, there doesn't seem to be any continuity or a good transition period... [C10]

One carer, however, did experience effective continuity through having a named transition nurse and found them to be an invaluable source of information and support to navigate the transition process:

I don't think it would have been half as easy without the transition nurse, you would just have these appointments arriving, telling you to turn up at the health centre for your first vent team. You wouldn't know who...quite what it was for or who it was. (...) the transitions nurse was a really good resource. [C07]

Lack of coordinated planning

Parents described a lack of coordination, which created uncertainty about who would take over responsibility of care or actions to take in a crisis situation. This in turn increased their child's vulnerability:

(...) there was to be one meeting where the [Adult Hospital] nursing staff were to come up to the [Children's Hospital] to meet Hannah, that they called off that morning, that never happened. So, we were discharged from [Children's Hospital] having not met anyone from the [Adult Hospital], and all this time Hannah's legs were getting worse and worse and Hannah was getting worse and worse. [C09]

There was often a sense of there being a lack of responsibility for multiagency coordination, resulting in a transition being largely service-driven rather than person-centred. This gave parents little confidence in the quality of this process:

(...) we used the tool book in person-centred planning that I had provided because I had been away on a course and everybody filled things out, but nobody wanted to take responsibility for it and nobody wanted to collate it. So that process has not been followed through, so I don't think for Richard his transition has been person-centred at all. [C04]

However, some carers gave examples of excellent coordination and multiagency planning between health and social care, who worked together to ensure a well-managed transition process:

There was a lot of multiagency planning in the run up to Mark's transition, which as I said was both health and social care. I think that is a really key thing to have and if you can have the same people and people who know them well and that plans are put in place as best they can. [C02].

Confusion and the state of unknown

This feeling of confusion and uncertainty about future care seemed to be further reinforced by the lack of access to reliable and consistent information:

I know what's happening with regards to therapy, but I don't know what's happening exactly and the paediatrician when I spoke to her she thought it was the paediatric orthopaedic surgeon that would see Richard and she did write to him. It's only since then that we've discovered that that's not the pathway, so she didn't know. [C04]

Parents expressed feelings of confusion about accessing services and expert advice, and were often excluded from communication between professionals or not provided with clear points of contact in adult services:

(...) you're not quite sure which route you're supposed to be going. You know, who to contact? Who's you're first port of call? [C01]

Parents making transition happen

Parents as transition coordinators

The poor coordination and management of the transition process led to many carers having to take responsibility for ensuring there were no gaps in their child's care. Parents in this study were found to take initiative on anything from initiating the transition process and handover between professionals to organising training for staff, daytime activities and referrals to adult services:

It's taken me sort of saying 'I'm really worried about this', for them to say we'll refer to the spasticity service who will refer to a neurologist locally. (...) Things like that should happen without me having to ask for it; you know, she's got an ongoing condition, it's never going to get any better. [C10]

Taking a very proactive approach and becoming the driving force behind transition planning demanded focus and perseverance, however it was often the only way to ensure a successful outcome. Although the majority of the participants appeared to have the skills and ability to act as strong advocates for their children, as one carer pointed out some people with complex ID can be disadvantaged if their parents are not in this position:

(...) not everybody has the skills, and that's not a criticism. Not everybody has the time, people are working full time. We were semi-retired when we came up here, so this could be our life's work. Other people, they've got other children, we've only got Duncan. It's easier to make that our entire focus. [C05]

One carer highlighted how having support from a dedicated professional, in this case a transition nurse, can make a significant difference to the experience. Some of the areas of support that this mother appreciated most included identifying suitable day care provisions, making specialist care and training arrangements, preparing letters and reports to support funding decisions, liaising with consultants, helping identify appropriate adult health care services, advocating for the family, providing emotional support and guiding the family through the transition process:

She met with us, she was involved in the transition from school to adult services to adult day services, I suppose, really, from a social work point of view, but she was also involved in the sort of health aspect, and she was like your sort of champion. [C07]

The battle of transition

Despite taking responsibility for coordinating many aspects of the transition process, parents reported an overwhelming feeling of having to “fight” or “battle” for services that their children were not only entitled to but were often essential to their health and wellbeing. This included accessing appropriate treatments, care service provisions, funding or timing of leaving education:

So, once we had quashed this age 16 leaving school, no sooner had we done that than we were battling leaving at age 18 (...). So, we then found ourselves in a battle on when would his transition begin. Although a council funding issue, the date obviously impacts on NHS as well. Paediatrics need to know. [C05]

Parents described many struggles to access services and appropriate care, needing to act as strong advocates for their child's rights. This demanded stamina for what they often perceive as a continuous fight:

I've just come to the conclusion everything is a struggle. Everything is arguing the toss, sort of on bended knee, 'could we do this? could we do that? it would be really helpful...'; (...) and I think it is sad, it's quite sad that it's not a standard. [C07]

A shock to the adult health care system

Unprepared adult services

Parents' first experiences of adult hospitals were rarely described as positive and the participants gave the impression of the young adults with complex ID causing a "shock" to the adult health care system. Parents viewed services as being unprepared for their level of complex needs and lacking essential adaptations, including appropriate hoists, changing facilities, suitable beds or monitoring equipment. This placed additional pressure on parents, who sometimes had to source the essential equipment themselves.

Adult hospitals tended to lack facilities for parents to stay overnight, even though most parents did not feel able to leave their child alone. They reported instances where adult health care professionals lacked training or knowledge of the specific medical equipment or technologies that had been commonplace in the paediatric settings:

(...) the PEG came out three times while he was in the hospital and this is a PEG that had never come out before ever in like the ten years he'd had a PEG in. We were a bit concerned they weren't maybe...and they admitted themselves they'd never seen a PEG like that before. [C02]

(...) quite often when I'm with Andrew I feel I'm ground breaking sometimes, thinking, what, have you never come across somebody with an established trachie? [C07]

Such experiences reinforced parent's perceptions that many adult health care professionals might lack essential knowledge of ID, nor have skills and experience to recognise and appropriately respond to the complex needs of this population. Furthermore, they felt that the staffing resource to provide adequate care was often

not there. This increased parents' anxiety and further diminished their confidence in the quality of care their children received:

(...) my 20-year-old doesn't speak, can't move, can't press buttons, can't get anybody's attention, (...) she could be just left there if nobody's seeing to her. She's not able to say that she needs changing or she's hungry or thirsty or that, you know, and that really worries me, and that's down to lack of numbers to be honest, lack of staff. [C10]

The paradox of adult hospitals

The interviews revealed that standard hospital procedures were not always adapted to take account of legal guardianship. Parents often felt dismissed and not listened to, such as during hospital admissions, where they might have been asked to wait in another room while their child was undergoing assessment:

It did feel like that was unnecessary. We could have helped them. They didn't know anything about Mark. They didn't know anything about physically what he would be like or his communication other than what we filled in which would be quite basic when we first went into A&E. [C02]

Although some health care staff were described as open and receptive to parents' suggestions, others were perceived as very resistant to accepting their guidance:

(...) it was a long process to get a person who could actually listen and take on board what I was saying...to go through the notes to find out what happened on the previous occasion. [C01]

Excluding parents and cares from the process of assessment, decision-making and care did on some occasions lead to serious, potentially life-threatening mistakes:

(...) the day before he was due to leave, we realised they actually hadn't been giving him the right medication. (...) We then realised he hadn't been getting the right amount of bolus feeds because again nobody had really asked us and in fairness, I hadn't really thought about it. It was partly our fault as well. [C02]

At the other end of the spectrum, parents could sometimes be made to feel fully responsible for medical decisions, which diminished their confidence in the adult team

being able to provide appropriate care. As a consequence, some even turned to their old paediatric team for support:

They didn't hoist Hannah out of her wheelchair. They didn't feel her [tone]. They asked me what did I want to do? And I kind of looked at them to say, well, yes, I am the best person who knows Hannah, but that was always a decision made by a clinician at [the Children's Hospital] (...). So, in the end we didn't really do anything. Came home. (...) and in desperation I picked up the phone to our old neurologist, who was absolutely fantastic. He said, bring her in. [C09]

Some parents gave examples of excellent practice in the adult hospitals, with nurses and other staff readily adapting standard procedures and working with them to ensure that their children's stay was as smooth and comfortable as possible:

They even said we can get a bed down from the children's ward so you can stay over, (...) but actually they managed to reassure me that...I was sufficiently close to the hospital, a ten-minute drive, and they were going to take good care of him, that I felt that I could leave him. [C07]

Lack of continuity of care

The interviews highlighted lack of continuity of care between children and adult health and social care services, with limited availability and access for young adults with ID. In some cases, this threatened the continued therapeutic input and monitoring of conditions:

Richard was also seen by the vision service because he has an eye condition and a processing condition and again their priority is 0 to 19. So, he's not going to get that same level of input just because he's become an adult. [C04]

This sudden drop in services, which seemed to be guided by arbitrary age criteria rather than a clinical need, made parents feel abandoned and that their child's health was not a priority anymore, despite their ongoing very high levels of needs. Parents described falling between the gaps of services due to poor coordination and rigid criteria resulting in them being left without support for extended periods of time:

(...) she ended up in hospital for three months, she came home having a central chest line in, having antibiotics that I was doing (...). And the [children's community] nurse,

that time I could have done with some support, but I never saw her again.... [She] stopped seeing her at 16, but the adult nurses don't pick them up till they're 18. [C10]

There was an overwhelming sense that young adults with complex ID do not readily fit into the adult health and social care systems including day centres, respite and complex care facilities, and that parents encounter multiple barriers when trying to access services and resources:

(...) everything that I do for Andrew ... I feel it's ground breaking. They make decisions for Andrew and Andrew alone, because that's what they told me when they did his day centre. They said, 'this is for Andrew and Andrew alone', presumably to sort of cover themselves to say, well, if somebody else comes along and says, how come Andrew's going there? they say, well, that was a unique one-off decision. [C07]

However, there were also examples of good continuity of care, with nurses helping parents establish points of contact in specialist adult health services. This seemed to give them more confidence that they would be able to access help when required:

Very much the specialist nurse, who is a lovely, lovely person. She has linked to the spasticity management consultant, and obviously a lot of Hannah's issues are tone based, or can be tone based, and she can always be contacted on our behalf. We don't see her every time, but she can also be contacted. So, we now have the two prongs, so to speak, through the specialist nursing staff that hopefully would access us up, yeah. [C09]

The unbearable pressure

Parents taking responsibility for health monitoring

Diminished services that were more difficult to access, coupled with a lack of regular input from the adult health team led to parents having to take more responsibility for monitoring their child's general health and complex conditions. Even with successful transitions to specialist services, the young person was sometimes immediately discharged from the adult service with nobody charged with monitoring their condition:

We did get referred to the adult service well in time, we saw the adult doctor once, had us back another time and then discharged us. And that I find hard, I mean, she's got

ongoing problems, she's on a really high dose of one drug to keep her gut working, and yet nobody's now looking after it but me, so you're left high and dry. [C10]

However, there were also examples of excellent practice, with one carer highlighting how good communication and agreeing a clear plan can help manage parents' anxiety about monitoring the young adult's health conditions and minimise waiting time:

We sometimes just need that instant access to the doctor to say, look, this is happening, do you think we should increase this drug?, because we know there's parameters within certain meds. The doctor will say, right, I would like you to do this, and I'm going to send you an appointment for three week's' time, and then we'll review how it's going. Rather than you go for the meeting and then you've got to make a change, and then you still don't know if it's going to work. So, all of the doctors agreed that I can contact them. [C05]

There were also excellent examples of General Practitioners taking a leading role in ensuring continuity of care, both in terms of managing general health as well as acute care:

This GP said to me, I would like to be Hannah's named GP. And now we just see him all the time and it's just...the difference is huge. [C09]

Alone in a new environment

Following the transition to adult health services, the pressure experienced by parents seemed to increase significantly. The first admission to a general hospital was often not only a stressful but also an isolating experience, with little support available to help parents navigate this unfamiliar environment:

There was no help, no advice. I have never felt so isolated in my entire life. (...) We did meet some very nice people along our way. But at the point where we were at the lowest we could possibly be was when we were going from the [Children's Hospital] to the [General Hospital] with nothing in place to back us or help us in the adult hospital situation. [C09]

This feeling seemed to be reinforced by the loss of the practical support offered by child health nurses, leaving parents responsible for most aspects of everyday personal

care while their child was in hospital. Even when a level of support was available in the form of ID Liaison Nurses, poor referral practices led to parents being missed and unable to take a break from caring responsibilities.

One parent who received support from an ID Liaison Nurse while her daughter was admitted to hospital, saw this role as invaluable and felt that the nurse was able to advocate for the family and help adult staff adapt their procedures:

I was able to explain the situation to her, and obviously she had a better understanding than the actual doctors had, so she could go and speak to the doctors, and then obviously, things kind of relaxed a bit and they were a bit more helpful. Which shouldn't have been the case, you know. [C01]

One mother described the gap in support she experienced after being discharged from the children's community nursing service, which left her feeling isolated:

There's no equivalent [to children's community nurse] in the adults, and they're a great source of reassurance and talking to...especially through things that are just everyday things, stupid things like bowel habits (...). But it does affect him if he doesn't go to the toilet, but also if you were concerned about him health-wise, his breathing or whatever, you could speak to anybody in the CCN office. [C07]

Impact on parents' health

The increasing pressure placed on parents as a result of transition and the reduction of services such as respite, complex care and hospice support was seen to impact on their own mental and physical health. Losing valuable support to deal with the workload of the hugely challenging task of caring for a person with complex ID had a significant effect on parent's quality of life, ability to continue working and could put a strain on their marriages and relationships.

I get 42 nights respite a year which is a hell of a drop down. My children's hospice is gone, so I don't get my three weeks there, and complex care, rather than having three or four visits a week or somebody helping out in the evenings for a few hours from half five to half nine. I'm lucky, I count myself lucky if I get one shift a week, and that just means that Andrew goes in the bath once a week, because I don't always have time to bath him. [C07]

Furthermore, the pressure of providing continuous care and support to their child in the hospital setting, along with a deep sense of isolation, could sometimes lead to a rapid decline of parents' mental health and affect their ability to look after their child:

They're very, very, very nice people down in the wards, but there was not enough of them to be able to say to me, go away for an hour, do something. So, I was with her constantly the whole time, physically drained and mentally on the verge of...I really was toiling hugely. [C09]

Given that the needs of the individual with complex ID remain the same or can sometimes increase, the demands placed on the aging parents was felt to be unrealistic and damaging to their health:

I get sore backs, I'm exhausted because there's no support. (...) The other thing, this year especially, I'm never ill, never ill, don't even get colds in the winter, but this year I have been ill and I'm sure it's because physically I'm so tired. (...) I could barely get off the settee, but I still had to shower two severely disabled young adults. [C10]

DISCUSSION

The population of young adults with ID living into adulthood is increasing, and is a phenomenon that will continue. Many have a range of lifelong, multiple physical and mental health conditions (Truesdale & Brown, 2017). As a result, more young adults with complex ID will require access to health care across their lifespan and will transition to adult health services (Hughes-McCormack et al., 2018).

The findings from this Scotland-wide study demonstrate that transition from child to adult health services often presents momentous challenges for people with ID and complex health needs and their carers. Although most of the carers in this study rated their overall experience of health transition as positive, the language associated with the emerging themes is evocative of largely negative experiences, as they described: "a deep sense of loss", "an overwhelming process", "a shock to the adult health care system" and "the unbearable pressure".

From the family carers' perspective, transition to adult health services is a highly emotional time of major changes and the results from this study underline the areas of support that could be most helpful and meaningful for parents. Nurses were

identified as an important source of support during this period, with opportunities for involvement in transition planning, communication, ensuring continuity and providing support.

Carers repeatedly emphasised the sense of loss of long-standing relationships with nurses and other health professionals within child health services, echoing other studies focussing on transition for young adults with ID (Bindels-de Heus et al., 2013). As a result, they frequently viewed future care in adult services with great uncertainty. For most carers the process of transitioning from child to adult health services was stressful and bewildering, which mirrors findings from previous studies (Leonard et al., 2016; Young-Southward et al., 2017a). The lack of coordinated and person-centred planning and limited access to reliable information while trying to establish a new care team in adult health services often left parents feeling confused and anxious about future care (Schultz, 2013; Okumura et al., 2015; Bhaumik et al., 2011).

Parents of young adults with ID often viewed their children becoming more vulnerable following transfer to adult services. As well as needing more information about new services, they lacked detail on the legal dimensions (such as guardianship) that would allow them to remain fully involved in decisions about their child's health care (Davies et al., 2011; Betz et al., 2015). Putting these legal processes in place can take time, yet the findings from this study indicate that the actual transfer to adult services could often be quite rapid, with little or inadequate preparation for this essential matter.

Many carers felt they needed to assume responsibility for the transition process in order to ensure the needs of their children continued to be met. These findings correspond to those in a recent systematic review of the international evidence (Brown et al. 2019), that identified a theme of "parents as advocates in emotional turmoil". This theme captured carers' sense of having to "fight" for services while navigating a maze of confusing information. While families want to be at the heart of the transition process, they do not want to assume full responsibility for every aspect of it (Crowley et al., 2011). Similarly, the findings echo previous studies indicating that faced with health care professionals' lack of proactive preparation, it is often parents' own resourcefulness that ensures a successful transition outcome (Davies et al., 2011).

However, carers in this study also highlighted the positive impact of some nurses' involvement in the process of transition, suggesting that they can play a central role in

preparing, educating and supporting young adults with ID and their families at the start of and throughout the transition process (Fegran et al., 2014). For instance, due to their involvement with the young person and their families over many years, child health nurses develop a wealth of knowledge and expertise in their needs (Betz, 2013). By collaborating with adult health nurses and other professionals, they are in a position to ensure person-centred care planning and handover. An integral part of the transition process should involve nurses providing opportunities for emotional support for young adults with ID and their families, to enable them to explore and discuss their concerns, hopes and future aspirations (Chu et al., 2015).

Some carers in this study benefited from the involvement of dedicated transition nurses, who they felt helped them navigate the transition process, provided support to access suitable adult services, advocated for the family and offered emotional support. The benefits of a “transition service coordinator” as an advanced practice role for nurses has been promoted by Betz and Redcay (2005), who argue that they can take a leadership role, act as clinical experts, consultants, promote change and educate. However, while such role development might be welcome, more evidence on its impact is needed (Brown et al., 2019).

Findings from this study support previous research suggesting that parents worry about availability and access to adult services (Woodward et al., 2012), or where they might feel excluded while their child is receiving care from adult care providers (Bindels-de Heus et al., 2013). Both current and existing studies suggest that parents view adult health services as ill-prepared for the multifaceted needs of people with ID, including knowledge of specialist medical equipment, necessary environmental and communication adaptations, or legal aspects of health care related to guardianship. Parents in this study highlighted the importance of their continued involvement in their child’s care in adult services, along with recognition for their expertise in their child’s health and other needs.

ID Liaison Nursing roles have been developed in many acute hospitals. They offer a potentially important area of support and advice before, during and after transitioning and improve continuity of care (Brown et al., 2016). Several parents in this study highlighted the role of the ID Liaison Nurses in hospital settings, in ensuring appropriate adaptations are made and acting as points of contact for easy access to

specialist health services. Whilst these roles exist in some countries, evidence indicates that there remains widespread issue in addressing the barriers to accessing health care (Hepburn et al., 2015). Given the concerns regarding unmet health needs and access to health care, further developments are needed if the population of people with ID and their families are not to be further disadvantaged, particularly at the point of transition from child to adult health care and beyond (Cheak-Zamora & Thullen 2017).

Another important issue highlighted by the current study is the detrimental impact of transition to adult services on the health and quality of life of family carers of people with ID. The negative experiences of transition as well as pressures experienced as a result of decrease of services following transition can affect parents' physical and mental health and consequently their ability to care for their children.

The findings from this research can be contextualised in Meleis et al.'s (2000) Transitions Theory, which has been widely utilised in nursing research and practice (Arrowsmith et al., 2016; Munck et al., 2018; Brown et al., 2019; Lindmark et al., 2019). This theory recognises transition as a complex and multidimensional process and provides a framework for characteristics and indicators of healthy transition processes. It suggests that better understanding of transitions could lead to development of "nursing therapeutics" or interventions to assist individuals and their families with managing transition (Meleis et al., 2000). The theory focuses on the role of nurses in increasing awareness and facilitating engagement throughout and providing support at the key points during the process. The findings of this study emphasise nurses' role in recognising stress, anxiety and confusion often experienced during the transition process. Furthermore, by drawing on their extensive knowledge and skills they can support patients and families to significantly reduce these feelings.

This study adds to the body of international research on transition by highlighting the complexity of relationships and interactions between family carers of people with complex ID and health care professionals. Similar observations were made by Davies (2005), who tested Meleis' transition theory in the context of relatives' experiences of move to a nursing home. They found the relationship among the care home staff, the resident and their relatives to be reciprocal rather than the family and the resident simply being passive recipients of care. The current findings suggest a similar

perception among parents of people with complex ID and highlight the urgent need to acknowledge both the needs as well as the role of family carers at the point of transition. This is not only to facilitate a more effective transition but also to ensure carers' health and wellbeing is not affected as a result.

CONCLUSION

The majority of young adults with ID continue to live at home with their families who play a central role in their on-going care and support. International research evidence highlights that this population is living longer with a range of interrelated complex physical, psychological and behavioural support needs, and more will transition from child to adult health services. There are therefore important implications for nursing practice. For some, the transitions process is complex and poorly coordinated, leading to stress and anxiety and the potential for poor health outcomes. Families want to be involved in the transition process, however they do not want to feel that they are responsible for ensuring that all the needs of the young person are met. Young adults with ID and their families can experience a sense of loss when trusted and well-known practitioners are no longer involved following transition. There is an opportunity for nurses to play a central role in coordinating the transition process, thereby helping to ensure that the needs of young adults with ID and their families are effectively identified and met.

Relevance to clinical practice

The findings from this study highlight that nurses have an important role in effectively assessing, planning and coordinating the complex and multimorbid health needs of young adults with ID across all health care settings. Central to an effective transition is the completion of comprehensive assessments and care plans, required to inform future treatments, interventions and support needs (Rochester-Eyeguokan et al., 2016). Nurses are in a key position to ensure collaboration and effective information sharing with other nurses in primary and acute care as well as specialist ID services (Gray et al., 2017).

There are opportunities for nurses to lead on the development of transition pathways, which have been found to be effective in other areas of nursing practice, such as cystic

fibrosis (Coyne et al., 2017; Wells & Manning, 2017; Burke et al., 2018). Such pathways would enable nurses to work with the young adults with ID and their families to provide information about the transition process and how their care and support will be provided in the future.

Nurses and other health professionals do require education and support to respond to the legal context regarding health care decision-making for young adults with ID, to ensure that their practice meets legal requirements and family members are supported effectively through the transition period (Johansen & O'Brien, 2016; Shay and Lafata, 2015).

Strengths and limitations

The strengths of this study lie in obtaining the voices of family carers of young adults with ID who experienced transition across many different health systems. Seeking their views and experiences in order to offer solutions can ensure transition is person-centred and responsive. Recognising the concerns of families presents an opportunity for health services to improve practice. The limitations relate to the sample involved being family members who expressed an interest and had the time to participate, and they may not be wholly representative of all families of young adults with complex ID who have gone through the transition process. Additionally, the study was undertaken in one part of the United Kingdom and may not be reflective of the experiences in other parts of the country or internationally.

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DEMOGRAPHIC INFORMATION		
CARERS		
Relationship to the person with ID	Mother = 9	Father = 1
Age	40-49 = 2	50-59 = 5
	Missing = 3	
Full time carer?	Yes = 8	No = 2
Overall experience of transition	Very positive = 1 Mostly negative = 2	Mostly positive = 5 Missing = 2
PEOPLE WITH ID		
Gender	Female = 4	Male = 6
Age	16-19 = 1	25-29 = 1
	20-24 = 5	Missing = 2
	>30 = 1	
Diagnosis	Genetic condition = 2 Cerebral palsy = 7	Autism = 4 Intellectual disability = 4

Table 1: Demographic information for carers and young adults with ID

A deep sense of loss	Losing the sense of safety Loss of integrated services A sense of isolation and vulnerability
An overwhelming process	Re-establishing a care team Lack of coordinated planning Confusion and the state of unknown
Parents making transitions happen	Parents as transition coordinators The battle of transition
A shock to the adult health care system	Unprepared adult services The paradox of adult hospitals Lack of continuity of care
The unbearable pressure	Parents taking responsibility for health monitoring Alone in a new environment Impact on parents' health

Table 2: Themes and sub-themes relating to family carers' experiences of the transition process

1. What was your experience of the transition process from child to adult health services for your family member? Can you briefly describe what that process looked like?

2. What was the role and contribution of different health professionals in children, primary care and specialist adult learning disability services in facilitating the transition for your family member? *Prompts: nurses, others / carer's role*
3. What has worked well during the transition from child to adult health services in your circumstances? What were the positives? *Prompt: anything else that works well when facilitating transition?*
4. What did the professionals do that you think was particularly helpful in facilitating the transition for your family member?
5. What were the challenges you have been faced with in terms of the transition process for your family member? *Prompt: what do you think health professionals could do to help facilitate a smooth transition / anything else that doesn't work so well in facilitating the transition process*
6. How do you understand person-centred and family-centred care and how important do you feel it is for the health care professionals to be person-centred and family-centred during the transition process? *Prompt: the role of nurses / health care professionals in facilitating PC and FC care*
7. What support would you require to ensure a smooth transition from child to adult services for your family member?

Box 1: Interview schedule