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Young Adults' Lived Experiences of the Transition Process from Paediatric to Adult Physiotherapy Disability Services in a college setting

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ABSTRACT

The transition process from paediatric to adult healthcare is recognised in the UK and internationally as a period of significance in a young person's life. The objectives of this study were to identify the young person's experiences of physiotherapy within: i. paediatric services, ii. adult services, and iii. the transition between the two services.

Semi-structured interviews with 7 young adults (19-23 years, diagnosed with complex and cognitive disabilities), who had access to on-site physiotherapy, occupational therapy and speech and language therapy, were completed at a third level college setting. Their verbatim transcripts were thematically analysed.

The experiences were mixed with both positive findings and some areas for improvements, leading to identification of four main themes.

- i. perceptions of physiotherapy service delivery
- ii. experiences of the transition period.
- iii. interdependence
- iv. recommendations for transition development

Recommendations included improved communication channels between paediatric and adult services and the involvement of young adults in research to assist in service developments.

Action is needed between paediatric and adult orientated healthcare services. Improved channels of communication, personalised transition interventions and availability of physiotherapy services are necessary to assist in positive transition outcomes. Creating connections and bonds between paediatric and adult services can have a significant impact on improved and smooth transition experiences for service users.

Introduction

'Transition' is a term commonly used to describe the process of moving from paediatric to adult services, the preparation prior to transfer and the settling period following the transfer of care and should involve the participation of both child and adult services throughout the process (National Confidential Enquiry into Patient Outcome and Death, 2018). The transition of young people with complex conditions into adulthood has been described as one of the major health care challenges of the twenty first century due to increased survival rates of young people with complex disabilities and chronic illnesses past childhood (McDonagh, 2005; Kennedy and Sawyer, 2008). This transition is a significant and difficult time of change for many young people. Heslop et al. (2002) state that we make many transitions throughout our lives, however one of the most important and life changing transitions is that into adulthood.

Disability is defined as having a physical or cognitive impairment which has a substantial and long-term adverse effect on the ability to carry out normal day to day activities (Equality Act 2010). In the 2021 census 26.7% of people under the age of 20 reported having a disability that either limits them a lot or a little (Colvin, 2023) and the financial implications of raising a child with a disability is three times greater than that of raising a non-disabled child (Contact, 2014).

There is a plethora of guidance on the appropriate steps to be taken to ensure successful transition of a young person from paediatric to adult healthcare services (Chambers, 2023; HSE, n.d.; NICE, 2016; Periton-Edwards et al., 2014; Together for short lives, 2018). These guidelines echo The National Service Framework for Children, Young People and Maternity Services' (2004, p. 119), fourth standard that "all young people should have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood". It envisions that with appropriate support, young people will transition successfully and be empowered to reach their full potential independence.

The National Institute of Health Care and Excellence (NICE) guideline on transition from children's to adults' services for young people using health or social care services sets out the importance of the transition process, presenting key principles such as the importance of transition planning, both before and after the transfer of care, and the need for supporting infrastructure to be in place (NICE, 2016). NICE additionally highlights the specific transition needs of young people with Cerebral Palsy (CP), particularly in relation to learning and communication and emphasises the importance of timely planning (NICE, 2017).

This guidance specific to CP, corresponds with the report 'Every Disabled Child Matters' (2015), where emphasis is placed on the need for improvement in coordination and communication of services, improved provision of information and tailored transitions for all young people with chronic and life-limiting conditions. The NICE transition guideline (2016) suggest that having a named worker to assist in the facilitation of a successful timely transition is essential, as well as utilising a personal 'folder' or 'health passport' to assist in the preparation for the transfer of care.

Despite evidence and guidelines to support the benefits of a structured transition process it is evident that effective transition principles are not frequently reflected in practice (van Staa et al. 2011; Nagra et al. 2015; NICE, 2016). The 'Being Disabled in Britain' report (Equality and Human Rights Commission, 2017) highlights the difficulty faced by the UK Government, Clinical Commissioning Groups and NHS Trusts in identifying and understanding the inequalities faced by people with disabilities due to limited data collected by NHS providers.

The aim of this research was to explore the lived experiences young people have of physiotherapy services during the transition process, in order to build a knowledge base in this area of physiotherapy. The main research questions for this study are: 1. What are the experiences young adults have of the transition process between paediatric and adult services? 2. What are their perceptions of physiotherapy during the transition period? 3. Do these young people have any recommendations on service improvements for other young adults with complex physical and learning disabilities, based on their personal experiences of the transition process?

Methods

A phenomenological qualitative research approach (Miles et al, 2013) was chosen to the study of individual's lived experiences. Semi structured interviews allowed for participants to be asked the same questions within a flexible framework and allowed them to expand on areas of interest to them, guiding the interview (Dearnley, 2013).

Data sample and recruitment process

This research was completed in accordance with the Research Governance framework for Health and Social Care (Department of Health, 2005), the CSP Code of Members (CSP, 2011) and the Health and Care Professions Council Standards of Proficiency for Physiotherapists (HCPC, 2013). In order to uphold information governance and to comply with the University of Cumbria's Code of Practice for Research (2018), data collected and analysed for this study will be retained securely for a minimum of five years, before being destroyed in a secure manner. Ethical approval was granted from the University of Cumbria Ethics Committee, Carlisle.

Participants were recruited from a private college based in the northwest of England, all of whom have access to regular on-site physiotherapy, occupational therapy and speech and language therapy. Recruitment was initiated through contact with the lead physiotherapist at the college. Participant information and consent forms were distributed via email and in hard copy format to all participants as format preference varied amongst students depending on visual needs and the use of augmentative and alternative communication devices (AAC). Sampling criteria included students who identified to have recently transitioned between paediatric and adult services, or were currently transitioning between services, and were willing to engage in a semi-structured interview setting using verbal, AAC, sign language and assistance to communicate their experiences.

Data collection

Open questions (example "Is there any improvements you would like to see as part of your physiotherapy as a young adult?") were used giving participants the opportunity to discuss their experiences and feelings in their own way. At times, the researcher was required to follow an open-ended question by a closed question, as some participants had difficulty processing the amount of information in the question. Strategies such as providing an interview guide one week prior to the interviews, additional time during the interview and rephrasing of questions were used to ensure information would be interpreted without issues by all participants. The guide was discussed with the college communication and skills liaison officer to ensure language used was appropriate prior to distribution to participants. Once finalised, transcripts were provided in hard copy or via email to all seven participants to review before data analysis, as outlined during on the participant information sheet.

Data analysis

Thematic analysis was completed using the six-step approach outlined by Braun and Clark (Braun and Clark, 2006). Interviews were transcribed verbatim from the audio recordings. Transcripts were catalogued and indexed, providing all raw data with a unique serial number (e.g. P1; participant 1). Inductive thematic analysis of the transcripts allowed for themes to be deduced, an abstract and generalised statement to be formed on the transition process from the raw data collected in the interviews.

Results

Study population

Seven young adults, who had experienced a transition between paediatric and adult physiotherapy services were recruited. These were four females and three males, aged between 19-22, varying from first to third year college students. Six of the participants were members of the college student's union. One male and one female participant completed the interviews using augmented and assistive communication (AAC) systems and eye gaze technology. Six of the participants were long term wheelchair users, three utilising motor-powered wheelchairs. The participants included four residential students and three-day students. One student had an

adapted schedule allowing him to be a residential student during the week and returning home every second weekend.

Inductive thematic analysis identified four main themes and a number of sub-themes as shown in Table 1. These are discussed in turn below.

Table 1: Themes and sub-themes

1	Perceptions of physiotherapy service delivery <ul style="list-style-type: none">○ Physiotherapy input at college/home○ Paediatric physiotherapy service experiences○ Change in physiotherapy regime between services○ Service improvements
2	Experiences of the transition period <ul style="list-style-type: none">○ Overall positive experience○ Disjointed transition process○ Use of transition interventions
3	Interdependence <ul style="list-style-type: none">○ Role of stakeholders (parents and key workers)○ Importance of college for young adults and future planning
4	Recommendations for transition development <ul style="list-style-type: none">○ Improved communication strategies○ Involving young adults

Theme 1: Perceptions of physiotherapy service delivery

Young adult's perceptions of physiotherapy service delivery was overwhelmingly positive. All seven participants reported receiving physiotherapy input at a minimum of twice a week in college. The participants echoed the significance of physiotherapy input, praising the college therapists for their input: "they are really excellent" (P2). Independence given to the students in relation to their physiotherapy sessions was noted when one student reported the ease at which sessions could be accessed and the flexibility of sessions around the student's busy day schedule, attending sessions "whenever I can really" (P7).

Two students associated the move to adult physiotherapy services with better equipment availability:

"I have access to equipment, some that I'd never even seen before" (P1).

When asked what the main changes were in their physiotherapy regime one participant reported "access to different activities such as movement harnesses" (P3) as being a significant improvement. One young adult summed up the importance of physiotherapy on his daily life with a powerful statement:

"to be honest without physios I don't know where I'd be. Cause I'd be in pain all the time" (P1).

Recommendations for further improvements in services within the college were noted by two participants, with the possibility of increased hydrotherapy sessions and additional therapy led sessions.

Theme 2: Experiences of the transition period

The positive attitudes of the young adults towards their transition experience was drawn from all interviews. Although the transition processes experienced by each individual varied widely, overall satisfaction was evident:

"it's just been a great experience", "I wasn't chucked in at the deep end. The physios sent me a care plan before I started" (P1).

One young adult felt that the transition was disjointed at times as there was an absence of preparation in the paediatric services prior to the transfer of care, therefore adjusting to new systems was quite difficult.

“There wasn’t much in the way of a handover. It’s far better now than it was” (P4).

Despite all students reporting satisfaction with their transition period, not all students completed specific transition interventions to assist in the process. A collection of interventions was noted within the sample group: i. Multiple pre-transition therapy assessments, ii. Adult service visiting day, iii. Young adult and family induction day.

Theme 3: Interdependence

The roles of stakeholders were acknowledged by a number of young adults in the interviews. The stakeholders included parents and family members, the individual’s college key workers and the college therapy team. One student described the difficulty he had when faced with a decision of commuting to college each day or becoming a residential student:

“I love my family and I phone or facetime them every day. I made a bad decision. It is a long way on the bus. It made me realise how much I miss college” (P4).

This young adult and their key worker also recognised the unique position that the college is in whereby the needs of the students can be met through personalised planning relating to their commuting or residential status.

The importance of going to college was illustrated by two of the young adults. One student emphasised its significance in preparation for future planning.

“My aim for the future is to have independent living with support so I am determined to do well at college” (P4).

This student understood the gravity of independent living and the benefit of excelling in college will have on their future. Another student mirrored this opinion and included the importance of peer support and friendship in college. *“It was nerve wrecking at first, but I’ve got used to it now and I’ve loads of friends” (P7).*

Theme 4: Recommendations for transition development

The question of potential service improvements led to a consistent call for improved contact and communication between services. One young adult affirmed that services could be improved so simply if

“the old therapist could talk to the new one” (P2) prior to the transfer of care.

Another student emphasised the importance of including young adults, that have had experience of the transition process in research and service developments. It was very evident that participants were extremely keen to actively participate in the interviews, to provide an insight into their experiences, despite the demanding nature of the exercise.

“For him to maintain this level of concentration without thinking of phoning home, the reason is because he’s keen to help” (C4).

Discussion

Summary of findings

This research project uncovered meaningful responses from young adults regarding their experiences of physiotherapy services and the transition process between paediatric and adult services.

Positive experiences were expressed regarding physiotherapy services both prior to and after the transfer of care. Specific transition interventions were noted by a number of students; multiple pre-transition therapy assessments, adult service visiting day and young adult and family induction day, all of which had a reported positive impact on young adults' transition period, as they felt more prepared and less anxious about the transfer of care. Recommendations on the improvement of communication channels between paediatric and adult services was a central finding. Development of a fluid communication model between services would improve the care provided during the transition process, leading to a less daunting and stressful time for the young adults and their families.

Review of findings in light of previous research

The experiences illustrated by the young adults in this study support the premise that specific transition interventions could assist with smooth transfer experience for young adults during the transition of care. This finding reflects current literature surrounding the benefits of implementing transition specific interventions within healthcare services such as the 'Ready, Steady, Go' and 'On Your Own Feet Again' (Nieboer et al 2014; Sharma et al, 2014; Nagra et al. 2015). Furthermore, it corresponds to recommendations by the World Health Organization (2016) and NICE (2016) on the implementation of specific transition interventions to provide safer and more effective transition periods for vulnerable patients and service users.

The participants' reflections on the importance of communication and the need for improved communication between professionals and services mirrors current literature on healthcare service improvements (Betz et al 2013; Carrol, 2015). Lairviere-Bastien et al (2013) reported similar findings in which a lack of communication and transfer of patient medical records were identified by young adults as significant issues that could negatively impact the transition period for them.

Although research relating to physiotherapy and the transition period is limited, the findings of this research support those of Freeman et al. (2018) where the importance of communication and dynamic sharing of information between paediatric and adult services, beginning early in the transition process is advocated widely by both young people and parents. Although the specific healthcare services are not mentioned, it could be interpreted and supported by Myers et al (2020) that physiotherapy input should contribute significantly, given its role in management of people with CP. Current findings are also comparable with Moses et al (2016) and Lee et al (2017) where physiotherapy services are viewed as particularly valuable in assisting in the transition pathway through exercise and interventions such as motivational strategies to enhance engagement and independence.

The significance of inclusion of young adults in research and service improvements was a powerful finding. Participants felt strongly about being included in research in order to improve services for their peers. Research worldwide has emphasised the significance of including young adults with developmental delays and chronic conditions in research surrounding the transition period, as they have lived experiences of this process and the impact of change during a crucial stage of their lives (Carpenter et al 2012; Porter, 2013; Kerr et al. 2017).

Limitations to the research

This study was completed by a novice researcher, where interviewing young adults with significant needs was considered challenging due to inexperience in the varying communication strategies of the students. Critical consideration must be given to the positive findings in relation to the use of semi structured interviews.

For example, one student who used assistive and augmentative communication (AAC) was very reluctant to communicate using their device, instead opting for verbal noises and head gestures to communicate with the researcher, limiting the depth of information gathered. Ibrahim et al (2021) discussed the difficulty faced in capturing children's voices in the population with severe speech and physical impairments, and high levels of AAC abandonment, due to many factors including the lack of confidence when using new technology

Furthermore, due to the complex conditions of some of the young adults interviewed, one-word answers were used in response to a number of open-ended questions. In this situation, the researcher followed up with a less complex closed question, which may have affected the response given by the participant to that particular question. For this reason, the researcher had difficulty at times gathering detailed information on past childhood experiences of physiotherapy. On reflection, the use of multimodal methods, involving the use of indirect methods where a questionnaire style approach is not appropriate, may have allowed a more in depth, insight of the young person's experiences. These challenges have been previously described and remain an issue for many researchers. (Connors and Stalker, 2007; Dee-Price et al 2021, Ibrahim et al 2021).

Finally, it is important to highlight that the research sample was limited to one private college in the northwest of England, catering specifically for young adults with complex physical and learning needs. Consequently, the transferability of these findings is limited.

Recommendations for further research

The findings of this research met the research objectives relating to exploring experiences in adult physiotherapy services and the transition period between both services, however, it was not possible to fully uncover the young person's experiences of paediatric services.

Future research may consider a larger cohort across a range of settings, to demonstrate the potential contrast in experiences of paediatric and adult physiotherapy services in this current climate. Additionally, placing a greater focus on the use of specific transition interventions and their perceived benefits may allow for a greater understanding of the effects of these interventions on the transition process for young adults, their families and the support staff involved.

Lastly, future research may consider including other stakeholders in the data sample. This would allow for the collection of their experiences, adding depth to the research from different perspectives. Gathering a variety of experiences would help understand the effects of the transition period on the community involved. A conscious effort not to substitute the young people's voices must be at the forefront of future research in this area. It is vital that rigorous research is promoted in this field in the coming years, to provide robust evidence on the need for implementation of guidelines and standards of practice, with the goal of providing an improved and inclusive service for all children and young adults in the UK.

Ethical and R&D Approval - Ethical approval was obtained through University of Cumbria ethic committee.

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