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Spaces of well-being among young adults with physical disabilities transitioning from pediatric to adult healthcare

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ABSTRACT

Background: Youth with disabilities are at risk of poor health outcomes as they transition to adult healthcare. Although space and place play an important role in accessing healthcare little is known about the spatial aspects of youth's transition from pediatric to adult healthcare.

Objective: To understand the spaces of well-being as youth with physical disabilities transition from pediatric to adult healthcare.

Methods: This study draws on a qualitative design involving 63 in-depth interviews with young adults (n = 22), parents (n = 17), and clinicians (n = 24) involved in preparing young adults for transition. All participants were recruited from a pediatric rehabilitation hospital within a metropolitan area of Ontario, Canada. Data were analyzed using an inductive content analysis approach that was informed by the spaces of well-being framework.

Results: The results highlight that within the 'spaces of capability' those with more disability-related complications and/or those using a mobility device encountered challenges in their transition to adult care. The 'spaces of security' influencing youth's well-being during their transition included: temporary (in)security while they were away at college, and health (in)security. Most of the focus on youth's transition included 'integrative spaces', which can enhance or hinder their well-being. Such spaces included: spatial (dis)connections (distance to access care), embeddedness (family and community), physical access, and distance. Meanwhile, therapeutic spaces involved having spaces that youth were satisfied with and enhanced their well-being as they transitioned to adult care.

Conclusions: In applying the spaces of well-being framework, the findings showed that youth had varied experiences regarding spaces of capability, security, integrative, and therapeutic spaces.

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Introduction

During healthcare transitions, young adults with disabilities are vulnerable to health problems and increased hospitalizations.^{1,2} Transitions from pediatric to adult healthcare are often fragmented because of challenges with accessing healthcare, ineffective inter-agency communication, and location of services.^{3–9} Geographical and social spaces affect transitions because pediatric is often a one-stop-shop of specialty services, whereas adult services are dispersed. Focusing on transition-aged youth with physical disabilities is salient because they are at a critical stage of development and also at risk of adverse health outcomes.^{10,11}

Although research on transitions to adult healthcare is growing,^{3–9} the role of space (e.g., geographical, social, and therapeutic) during youth's transition to adult care is under-explored.^{12,13} Examining space and geographic location is salient because it is a social determinant of health and an under-explored component of the International Classification of Functioning, Disability and Health.^{14,15}

Spaces of well-being

Spaces of well-being refer to the geographical, social, and physical places that can influence health. We drew on Fleuret and Atkinson's¹⁶ well-used framework^{17–23} on the 'spaces of well-being' to inform our understanding of youth's transition to adult care. Their model highlights space as an active agent in shaping well-being where space has a shared and personal meaning. A space of

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well-being includes four characteristics: it is capable, integrative, secure, and therapeutic.¹⁶

First, capable spaces refer to the combinations of functioning making up the state of a person—particularly the nature of settings.¹⁶ Having a disability can affect well-being through physical and social spaces of capability.¹⁶ The nature of a disability itself can influence individual coping and how others form social constructions of their disability.^{24–27} For example, many adult healthcare providers lack knowledge about child-onset disabilities and may be unable to provide care.^{5–7}

Second, integrative spaces refer to how social networks and spatial contexts (where people live and spend time) can positively affect health.¹⁶ For example, having social supports can enhance access to healthcare,^{13,28} while lacking support is associated with social isolation and poorer health.^{3–9}

Third, spaces have varying degrees of security (e.g., environmental, health) affecting well-being. Secure spaces refer to how support can generate informed understandings and a degree of protection from risks. For example, young adulthood is a time when youth become more independent and may be at risk of health insecurity as they transition.^{3–9} They are responsible for arranging their healthcare appointments and transportation, which is difficult for those who do not drive, and lack access to public transit.^{29–31} Such issues related to access are critical because distance to healthcare is associated with reduced health utilization and increased risk of poor health outcomes.^{14,15,32}

Fourth, therapeutic spaces including urban greenspaces, community gardening, and even everyday spaces can have positive benefits on well-being.^{20–23,33–35} Such spaces have potential to renew weakened competencies and moderate the effects of disability (i.e., the nature and character of a place can offer healing).³⁶

This model provides a useful tool for understanding how spatial contexts shape well-being and shifts the focus away from individuals towards intersectorality where relational and situational approaches are central.^{16–18,33} This model moves away from focusing on well-being as an outcome and encourages us to think about it as a process, which is useful for exploring youth transitions. This research addresses an important gap because the spaces of well-being are under-studied in geography, particularly as applied to youth with physical disabilities.^{16–22}

Methods

Design and sample

The objective of our study was to understand the spaces of well-being as youth with physical disabilities transition to adult healthcare. We used an in-depth qualitative design, which is a secondary analysis of a larger study at one pediatric hospital within a metropolitan area of Ontario, Canada, where youth transfer to adult healthcare services at 18 years. A research ethics board at a pediatric hospital approved this study. All clinicians at the pediatric hospital involved in preparing youth to transition ($n = 62$) were invited to take part (24 consented).

All youth aged 17–25, who spoke English, had spina bifida, Duchene muscular dystrophy or complex physical disabilities ($n = 84$), and who were preparing for, or recently transitioned to adult healthcare, were mailed a package. We chose such types of physical disabilities because they provide a range of transition experiences for youth who often need connections to multiple adult healthcare providers. Those who consented were interviewed at a location of their choice. Interview questions focused on transition experiences, which is described elsewhere.^{4,6,7} Two research assistants conducted the interviews between July 2013–August 2016,

lasting an average of 35 min. Participants received a \$10 gift card as a token of appreciation for their time. Interviews were audio recorded and transcribed.

Participants

Participants included 22 youth aged 17–25 with a physical disability (i.e., spina bifida, Duchene muscular dystrophy or complex physical (i.e., multi-morbidities) disabilities), 17 parents, and 24 clinicians involved in preparing youth for their transition (see Table 1).

Content analysis

We used an inductive content analysis approach, which is useful for a large volume of qualitative data (63 interviews) on under-explored topics.³⁷ Content analysis involves three stages including preparation, organizing, and reporting.³⁷ In the preparation stage, the author and two research assistants independently read the transcripts while noting keywords related to spatial elements in transitioning (see Table 2). We used variations of keywords and applied them to all the interviews through NVIVO. Within content analysis, categories developed through engagement with the data, which involved reading all transcripts to understand the context of the interviews. Then, we read through the extracted quotes several times while developing a list of common themes which were compared and contrasted. We selected quotes reflective of each of the themes.³⁷

Strategies to support the credibility of the findings included having a rich variation in youth's spatial perspectives. Saturation of the data was reached around interview eight for youth and eight for parents for each disability type and 10 for clinicians, which is consistent with best practices in qualitative analysis.³⁸ In regards to the transferability of the findings we had representation from several disability types and various perspectives. The dependability of the findings was addressed by having consistent interview questions across the participant types. We kept an audit trail of analytical decisions.³⁹

Results

Our findings showed varied experiences among youth regarding spaces of capability (e.g., nature of the disability, lack of knowledge of adult providers), security (e.g., temporary health, in(security), equity, distance), integrative (e.g., spatial connections, embeddedness, physical access), and therapeutic spaces (adult healthcare providers, sense of well-being) (see Table 2 and Fig. 1). Although the themes are discussed sequentially they inherently overlap.

Spaces of capability

Some youth, parents, and many clinicians noted the influence disability had on youth's well-being. Those with more disability-related complications and/or those using a mobility device encountered challenges in their transition to adult care. For example, a youth explained, "I'm not very mobile ... It's difficult to get around" (youth-9). Another youth described: "the disability is more complicated than I'm able to grasp ... I should be able to go somewhere on a regular basis where they can help me" (youth-8).

During their transition, youth and parents described how some health providers would not accept patients with complex conditions; thus, making health spaces inaccessible. For instance, a parent (6) explained: "nobody will look after [her] because of her complexity"—referring to clinicians' discomfort and lack of knowledge with such conditions. A youth similarly mentioned how

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