



Heriot-Watt University
Research Gateway

“Crafting a ‘TransitionOmeter’

Citation for published version:

Levy, S, Wynd, AHD & Motee, A 2024, “Crafting a ‘TransitionOmeter’: A Proposed Framework for Developing and Honing Capabilities of Young People Transitioning to Adult Healthcare Services.”, *Comprehensive Child and Adolescent Nursing*, vol. 47, no. 2, pp. 86-97.
<https://doi.org/10.1080/24694193.2024.2348830>

Digital Object Identifier (DOI):

[10.1080/24694193.2024.2348830](https://doi.org/10.1080/24694193.2024.2348830)

Link:

[Link to publication record in Heriot-Watt Research Portal](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

Comprehensive Child and Adolescent Nursing

Publisher Rights Statement:

© 2024 The Author(s).

General rights

Copyright for the publications made accessible via Heriot-Watt Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

Heriot-Watt University has made every reasonable effort to ensure that the content in Heriot-Watt Research Portal complies with UK legislation. If you believe that the public display of this file breaches copyright please contact open.access@hw.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



“Crafting a ‘TransitionOmeter’: A Proposed Framework for Developing and Honing Capabilities of Young People Transitioning to Adult Healthcare Services.”

Sharon Levy, Andy H D Wynd & Ashmika Motee

To cite this article: Sharon Levy, Andy H D Wynd & Ashmika Motee (07 May 2024): “Crafting a ‘TransitionOmeter’: A Proposed Framework for Developing and Honing Capabilities of Young People Transitioning to Adult Healthcare Services.”, Comprehensive Child and Adolescent Nursing, DOI: [10.1080/24694193.2024.2348830](https://doi.org/10.1080/24694193.2024.2348830)

To link to this article: <https://doi.org/10.1080/24694193.2024.2348830>



© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 07 May 2024.



Submit your article to this journal [↗](#)



Article views: 48



View related articles [↗](#)



View Crossmark data [↗](#)

“Crafting a ‘TransitionOmeter’: A Proposed Framework for Developing and Honing Capabilities of Young People Transitioning to Adult Healthcare Services.”

Sharon Levy, RN, MPhil ^a, Andy H D Wynd, MBE MIO^{b*}, and Ashmika Motee, MPH^c

^aUsher Institute, University of Edinburgh, Edinburgh, UK; ^bSpina Bifida Hydrocephalus Scotland, Glasgow, UK; ^cHeriot-Watt University, Edinburgh, UK

ABSTRACT

This paper focuses on an innovative approach to preparing children and young people, with Spina Bifida, to move from child-centered to adult-oriented healthcare systems. Reflecting on our role in delivering a national nurse led service, we set to identify and critique international transition tools in use for this population. Specifically, we aimed to identify the core capabilities and indicators of progression to successful transition, so that holistic interventions could be planned to match the needs of individuals and their carers. There were two phases to the study, initially focusing on a systematic literature review on transition tools and the specific items that these tools captured, including skills, abilities and behaviors. Phase two culminated in the articulation of a segmented and incremental “road map”, aligned with facets deemed essential for a successful healthcare transition. The reporting of the literature review (phase one) followed the PRISMA guidelines and shaped the qualitative element of the study (phase two) through the use of semi-structured interviews and thematic analysis. The search strategy yielded 11 studies, which were then manually searched for other relevant literature, adding a further 14 articles. The review analyzed 7 specific tools for spina bifida and 8 generic tools, which were deemed appropriate for this group of patients. A comprehensive list of core capabilities was then articulated and framed to fit a progression timeline. Specific interventions were formulated to explore ways to co-produce resources that could enhance and support a planned transition to adult-focused services. Our proposed mapping of capabilities and progression could shape other transition programs, where nurses work collaboratively with young people, carers and other members of a team. More work is needed to further explore and embed the framework that, as we did, could be digitized and shared with all stakeholders involved in the transition process.

ARTICLE HISTORY



Received 5 January 2024
Accepted 23 April 2024

KEYWORDS

Spina bifida; transition;
systematic literature review;
transfer of care; data driven
innovation

Introduction

Spina bifida is the most common congenital condition leading to complex disabilities and remains the most serious anomaly of the nervous system that is compatible with life (Blount et al., 2023). The condition is part of the umbrella term “neurological conditions,” which

CONTACT Sharon Levy  Sharon.levy@ed.ac.uk  Usher Institute, University of Edinburgh, CPD lead Data Science for Health and Social Care, Usher Building, 5–7 Little France Road, Edinburgh BioQuarter – Gate 3, Edinburgh EH16 4UX, UK.

*Present affiliation: Managing Director and Principal Consultant at Bute Consultancy

© 2024 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

affect the brain, spinal cord nerves and muscles. The severity of impairment is linked to the level of the spinal lesion and can manifest in a range of ways, including mobility difficulties and bladder and bowel continence challenges. Some individuals with this condition may also have cognitive difficulties related to executive functioning and attention. For young people with chronic neurological conditions and their carers, the transfer of care from child-centered to adult-focused services can be complex and challenging. This is observed in many parts of the world, where healthcare provision is shifting from a unified pediatric setting to being offered through multiple adult care providers in different locations (Betz & Coyne, 2020). Unlike other chronic conditions, where a global evaluation of interventions for effective transitions exists, there is little evidence that relates specifically to spina bifida (Logan et al., 2020). In a paper published in the *Scottish Medical Journal* in 2014 (Levy et al., 2014), we highlighted the harsh reality young people and their families faced while navigating the Scottish system at that time. Specifically, we noted the desire for a coordinated approach involving early and sustained transition planning and family involvement in the decision-making process. Others (Wright et al., 2016), focusing on cerebral palsy, noted that transition remains “problematic and vibrable” and despite a significant policy shift (Scottish Government, 2023) the challenges of embedding evidence-based practice into transition planning remain significant. We concur with scholars who see nurses as ideally suited to coordinating transition care, including the oversight of patients and parents’ education as well as quality monitoring and assurance (Holmbeck et al., 2021). We believe our nurse led project have implication and application to practice of others who support children and young people in other parts of the world, specifically in the global north including the USA, Canada and Australia.

The concept of transition is contested, and it is claimed there is no shared understanding among researchers, professionals and policy makers about an agreed definition (Jindal-Snape, 2023). The transition of young people with chronic conditions to adult services, is often characterized as a series of separate transitions involving stakeholders from health, education and social work. This approach fits well with the theory of multiple and multi-dimensional transitions (Jindal-Snape et al., 2019), which asserts that each individual experiences multiple transitions and that their transitions can also trigger transitions for others close to them. For example, the transition of a young person to adult care may coincide with the transition from high school to college and will impact parents who were the main carers and guardians in the past. Additionally, health transition is described as a process of moving from one phase to another while impacting on health status, triggering a period of vulnerability (Schumacher & Meleis, 1994).

Working with young people with spina bifida and their families to develop resilience for successful transitions (Levy et al., 2024), we are aware of the current experiences of service users as well as service providers. Such anecdotal evidence suggests that the use of a person-centered approach remains patchy and there is very limited provision of clear and accessible information to help in navigating a confusing transition terrain for young people with spina bifida. Yet the global evidence regarding the positive impact of a successful transition onto adult healthcare services is overwhelming.

There is a direct link between successful progression and increased independence, self-fulfillment, educational attainment and positive health and wellbeing effects (The Duffley Partnership, 2023). Ample evidence also exists on the negative impact of a failed transition that results in isolation, deterioration of health and wellbeing and disconnection from

services as adults (Hart et al., 2019; Stehouwer et al., 2017; Yeung et al., 2008). However, across the globe, young people, families and professionals seem to be facing similar challenges in navigating complex systems; finding relevant information; receiving person-centered and family-focused support; and providing adequate and integrated services, resources and staffing.

To explore a possible redress, we set out to articulate a transition journey that has a defined starting point as well as an end date. We also identified indicators of success, as some journeys may start and end but will offer very little in terms of desirable outcomes. Finally, we wanted to focus on the spina bifida population and to look at evidence from across the globe, specifically concerning the transition tools that are used in practice. In essence, we wanted to find a way to enable staff to be aware of, plan for and monitor the progress of transitions and involve their patients and their families in the process. Ultimately, we wanted service users to benefit from evidence-based and relevant input from all those who are involved in the provision of care. To this end, we crafted a digital element to be bolted onto an electronic health record, which we coined a TransitionOmeter. The digital environment enables access to records that can be shared with clinicians, carers and others who may contribute to the provision of holistic and person-centered care.

A review of valid and validated tools used to measure progression through a transition journey was therefore essential for obtaining relevant data that can guide appropriate interventions. We were seeking a baseline measurement to indicate the presence or lack of relevant capabilities, including skills, knowledge and behaviors, while setting an incremental progression path against specific stages of change. The matching of interventions to individuals, based on health behavior change theory, is reasoned to be more successful in enabling essential capabilities to be developed, honed and maintained over a longer period of time (Sawin et al., 2020).

Methods

This study involved two phases

Phase I: A systematic literature review focusing on transition tools and the specific facets or data items that were captured and the articulation of a segmented and incremental “road map” that matched the current transition principles in Scotland (Association for Real Change ARC Scotland, 2019).

The reporting of the literature review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Rethlefsen et al., 2021). The eligibility criteria were defined based on the following criteria:

Participants

Adolescents diagnosed with spina bifida/Hydrocephalus (primarily). Tools related to other chronic conditions (such as spina bifida) or tools measuring variables that are applicable to spina bifida were also included.

Exposure

The “exposure” in this review is referred to as the transition tool in terms of a measurement that facilitates the transition from pediatric care to adult healthcare. Studies focusing

primarily on transition programs or frameworks (not including measurements) were excluded.

Outcome

The primary outcome of this review was the measurement of variables linked to healthcare transition.

A standard search strategy was formulated based on transition tools used globally among youth with spina bifida; this tool was initially used in the MEDLINE database and included the following keywords: *spina bifida*, “hydrocephalus,” “transition tools,” “transition readiness,” “transition,” “adolescents,” and “younger.” The titles and abstracts of the studies were screened to find key papers as well as relevant index terms. The search strategy was improved following this trial and modified to adapt to other databases (see Table 1). The additional electronic databases used included CINAHL, PsycINFO and the Web of Science. To ensure that no potentially relevant studies were missed, a manual search of the reference lists of the included studies was carried out. The gray literature was also searched to reduce publication bias, to enable a balance of existing evidence and to enhance the understanding of this review (Paez, 2017). The gray literature included ProQuest Dissertation and Theses (ProQuest) and the World Health Organization (WHO). The identified studies were imported to and shared through the systematic review software Covidence, which was used both for title and abstract screening as well as for full-text screening.

Phase II: Having reviewed and critiqued the evidence we produced a list of capabilities and agreed on a start point and an end date for transition in the context of Scotland. We also formulated a set of questions that could be answered with a yes/no and relate to identified capabilities. These were categorized to match different stages of change through a consensus-building exercise among a small group of staff ($n = 5$). The SBHScotland ethics committee approved the study, and once the researcher signed a contract with the organization and gained access to an

Table 1. Final search strategy.

-
- 1 (Spina Bifida or neural tube defects or congenital brain malformation or abnormalities or myelomeningocele).mp.
 - 2 exp Hydrocephalus, Normal Pressure/e/or *Hydrocephalus/
 - 3 exp *Adolescent/or exp *Transitional Care/or exp *Child/or Transition tool*.mp. or exp **Continuity of Patient Care"/
 - 4 exp *Transitional Care/or exp *Patient Discharge/or Transitional care services.mp. or exp **Continuity of Patient Care"/
 - 5 (Transition* adj3 care).mp.
 - 6 (Transition* adj4 tool*).mp.
 - 7 exp *Transition to Adult Care/or Readiness tools.mp.
 - 8 Transi* app*.mp. or exp *Transition to Adult Care/or exp *Transitional Care/
 - 9 *Transitional Care/or *Transition to Adult Care/or Transi* program*.mp.
 - 10 Transiti* intervention*.mp.
 - 11 (3 or 4 or 5 or 6 or 7 or 8 or 9 or 10)
 - 12 Paediatric health*.mp.
 - 13 Pediatric health*.mp.
 - 14 (Adult adj3 health*).mp.
 - 15 (healthcare or care or service*).mp.
 - 16 adolescent medicine/or adolescent health services/
 - 17 (care or healthcare).mp.
 - 18 (P?ediatric? adj2 adult?).mp.
 - 19 (12 or 13 or 14 or 15 or 16 or 17 or 18)
 - 20 (1 and 2 and 11 and 19)
-

e-mail account and a digital storage space, they followed an engagement plan to recruit appropriate participants. Those who agreed to participate in the study were given information prior to being contacted to sign an informed consent form in advance of an online interview. Staff were asked to create clusters of similar capabilities, structured as a progression pathway, using the “Well Sorted” online template (<https://www.well-sorted.org/>). Together, we identified workflows, when and where capabilities could be assessed and by whom, and the resources that are available or should be developed to support young people and their families. Once this was agreed upon, we commissioned our technology providers to digitize the crafted TransitionOmeter and progressed usability testing, the details of which are beyond the scope of this paper.

Results

The search strategy yielded a total of 1,152 articles, from which 30 duplicates were removed. The remaining 1,122 studies were eligible for title and abstract screening. We excluded 1,076 records at this stage because they were irrelevant, leaving 46 articles for full-text screening. A further 35 articles were excluded because they did not meet the inclusion criteria. The remaining 11 studies that met the eligibility criteria were summarized in a narrative format. The reference lists of these 11 studies were then manually searched for other relevant studies, which yielded an additional 14 articles (see [Figure 1](#)).

Interestingly, no records were retrieved through a gray literature search.

The review identified 7 measuring tools pertaining to spina bifida and 8 generic tools, which were deemed appropriate for this group of patients. A further 6 potential tools that can be used for healthcare transition and are relevant to individuals with spina bifida were excluded, as the evidence of their applicability was not strong. The specific tools that focus on spina bifida include the following:

- (1) Transition Readiness Assessment Questionnaire for Spina Bifida (TRAQSB) (Wood et al., 2019);
- (2) Spina Bifida Life Course Model (LCM) (Dicianno et al., 2010);
- (3) The Adolescent/Young Adult Self-Management and Independence Scale (AMIS-II) (Sawin et al., 2018);
- (4) The Sharing of Spina Bifida Management Responsibilities Scale (SOSBMR) (Stern et al., 2021);
- (5) The Spina Bifida Independence Survey (SBIS) (Psihogios et al., 2015);
- (6) The Spina Bifida Self-Management Profile (SBSMP) (Wysocki & Gavin, 2006); and
- (7) The Kennedy Krieger Independence Scales – Spina Bifida Version (KKIS-SB) (Jacobson et al., 2013).

We also identified 8 generic tools, which we included in the analysis:

- (1) The Behavior Rating Inventory of Executive Function (BRIEF®) (Gioia et al., 2011);
- (2) The Adaptive Behavior Assessment System – Second Edition (ABAS – II)(Oakland & Harrison, 2011);

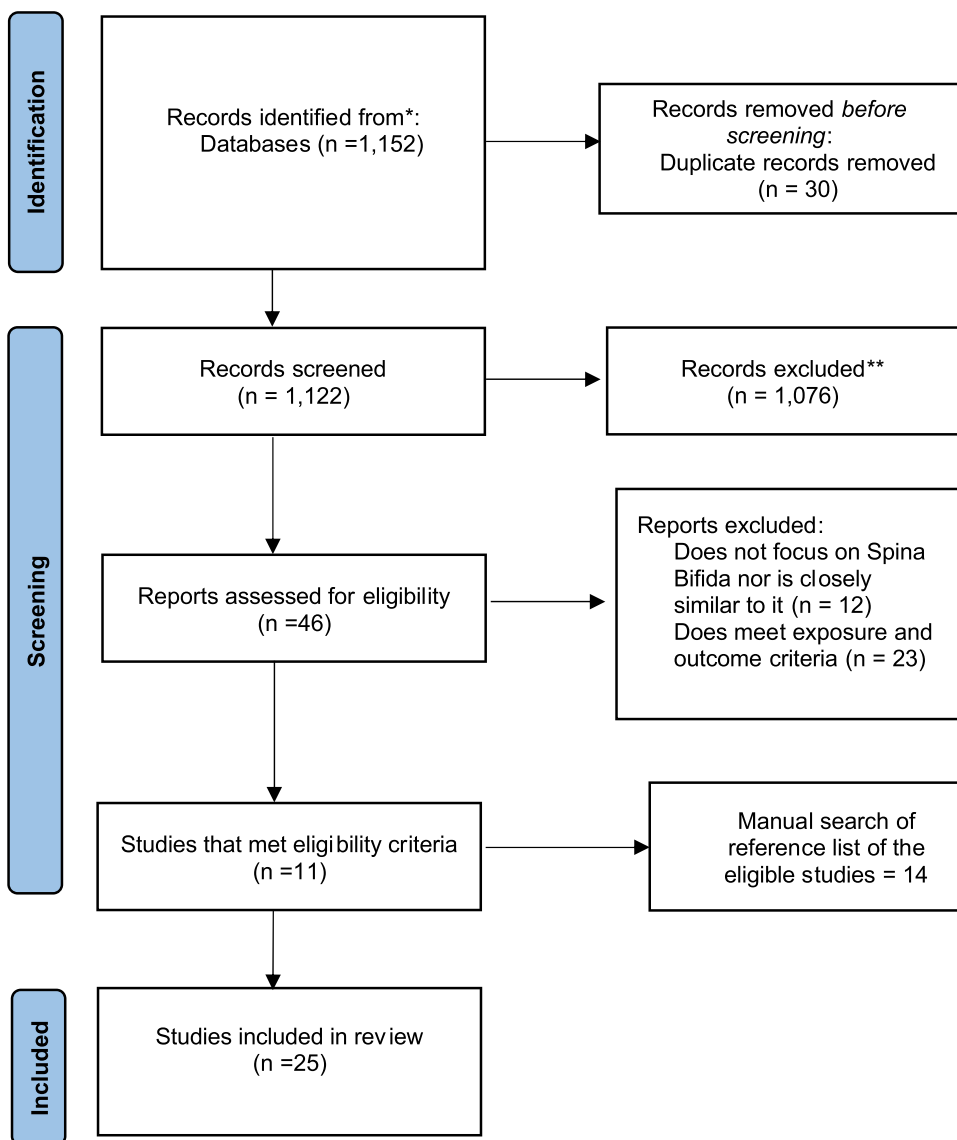


Figure 1. PRISMA Flowchart.

- (3) Self-Management Skills Assessment Guide (Williams et al., 2011);
- (4) The Successful Transition to Adulthood with Therapeutics=Rx (STARx) Questionnaire (Cohen et al., 2015);
- (5) The UNC TRxANSITION Scale (Ferris et al., 2012);
- (6) The Pediatric Evaluation of Disability Inventory (PEDI) computer-adaptive test (CAT): PEDI-CAT (Haley et al., 2011);
- (7) Ready-Steady Go (RSG) (Nagra et al., 2015); and
- (8) Family Interaction Macro Coding System (FIMS) (Stern et al., 2021).

The identified tools measured a range of capabilities, including self-management skills and transition readiness, whereas others were used to assess developmental milestones and functional ability; triage for problems; and planning interventions by a range of practitioners, including physicians, nurses, occupational therapists, neuropsychologists and counselors. Other facets that were measured included adherence to prescribed treatment, self-care abilities, social skills and communication, as well as the ability to manage intimate and personal care for specific medical issues on a day-to-day basis while knowing what to do in an emergency.

The number of items that were measured across the tools ranged widely, and some used a structured interview format for data collection administered by a trained professional, whereas others used a self-report questionnaire given to young people, their parents or both. The data captured included descriptions of subjective experiences as well as scores on scales that measured objective variables. Some needed a computer to complete the assessment or access to an online platform, and many used opinion statements and levels of agreement with these statements to indicate status and identify progression. Many tools require permission for use in research or clinical practice, and some payment is needed.

We also identified a number of tools that were based on a sound theoretical approach and recognized transition models. Indeed, many have addressed the issue of validity and offered results of statistical tests aimed at establishing internal consistency to affirm reliability. Surprisingly, and somewhat disappointingly, there was no consistency in the exact start point of the transition pathway, and a wide range of ages was noted, with an early age of 11 years for the RSG tool. This tool, incidentally, was the only tool we were aware of as being used in the clinical setting in Scotland for young people with neurological conditions.

The pool of questions we gathered through sifting the literature consisted of 111 yes/no/not applicable questions, 13 of which were excluded at this stage as irrelevant to Scotland. These included facets such as insurance options that do not apply to the services offered through the National Health Service (NHS). Staff members who were participants in the study were then asked to “sort” the remaining questions into segments that could mirror a progression pathway. They were also interviewed to capture their thoughts and views about their experiences of transition and about current practice. The final agreed consolidation of the TransitionOmeter consisted of 51 questions over 5 segments and was set to offer a structure, goals and scope of potential attainment as well as associated resources to monitor and hone needed capabilities.

A review of the qualitative data identified that the start of a Scottish transition journey does not have a set age but rather that, in some parts of the country, it has a firm end date: “... after the age of 18, it is inappropriate for them to be on a children’s ward, and it’s as simple as that. ... it is an artificial cut off, and I completely accept it does not take into account ... the level of developmental and emotional maturity.” However, in some cases, even if there is an attempt to prepare the child to move to an adult-focused service, there are barriers, including the parents themselves: “They come into a clinic as a 17-year-old, and their parents still answer all the questions that you ask even if you’re directing it at the young person. ... there is a real reluctance from ... some parents ... that aren’t ready for their children to grow up. ... it’s more about them letting go and letting their children have the chance to try things and to fail ... and then to succeed.”

The success of the transition process was also contested by participants who found it hard to articulate what it would “look like” for some of the young people they support. Staff argued that some young people with spina bifida will never progress to complete the entire journey, where they are ready to fully participate in an adult focused service. Some will only reach a specific level and stop progressing, as they will be unable to gain or hone capabilities that are beyond their physical or intellectual capacity. They all agreed that progression during the transition journey depends on right support by a dedicated person who works with the family over a period of time. In addition, an integrated “set up” is required in adult care where knowledgeable practitioners give young people more time during a consultation to advocate for themselves. There is currently no capacity or breadth of knowledge to support young adults with spina bifida, who are an anomaly in general adult clinics.

Discussion

To our knowledge, none of the spina bifida specific tools are currently being used in Scotland, and the only framework that has been explored with young people in an acute clinical setting in Edinburgh was the generic RSG tool. This highlights the challenges staff face in identifying appropriate tools and then consistently using these tools within clinical settings over a period of time. Reviewing the literature, mainly from the USA, it seems that this is not a unique finding and others face similar challenges in different parts of the world. It may be that the richness and variety of modes, scales and items make picking the right tool difficult. We acknowledge, however, that using valid and validated tools to shape the transition journey for young people with chronic and complex conditions is a desirable evidence-based practice. However, sometimes a radical change to practice has to start with a compromise, as long as patient safety remains intact and the security and confidentiality of the data are not compromised.

We believe that having a shared tool that staff, parents and young people themselves can access, as they initiate and progress their journeys, may help make the needed forward leap. Using a digital format may be an attractive gateway to those who are born into a digital world and who are hardly away from their mobile phone. Can we have an “App” that could help in digitizing the TransitionOmeter? Would a simple visual interface that clearly shows where the young person is on their journey, what skills they mastered and what capabilities are yet to be honed – be helpful? If so, how can we compile a library of relevant resources that can be aligned with capabilities, accessible and yet safe and secured? This was the challenge we set for our technology partners who were able to bolt this tool onto the ecosystem that is fed by an electronic health records. The way data are captured, as a by-product of a coproduction process, helps to develop ownership of targets and promote the use and sharing of relevant resources, among all that are involved in the transition process.

The desire to create an easy-to-use tool must be acknowledged when considering the limitations of this study. The Systematic Review itself, while expertly carried out to find relevant studies relating to spina bifida, had to add proxy conditions to overcome limited articles that were specific to this condition. That decision was made arbitrarily, and there could have been other papers relating to conditions that we failed to include. The qualitative segment involved a small population, and if more resources were given, it could have been more comprehensive. Resources were limited by the tight timeframe

set by the funders. The agreed constellation of the TransitionOmeter was not informed by a conceptual or theory-driven model but relied on the lived experience of those who are currently supporting young people and families in navigating the Scottish transition terrain. Finally, the “gaze” used to develop and construct the tool was tinted by the need to deliver a nurse centric outcome. Considering that transitions can be articulated as an ongoing process and holistic in nature, requiring psychosocial support and educational adaptations, further input from other stakeholders is merited in order to encapsulate a multi-faceted approach.

The implications for children’s nurses in practice

Nurses are often described as closest to their patient through the intimate nature of their practice. Those who care and support children and young people are also required to adopt a family centered approach and work closely with carers, while expertly deal with the rights of the parents and the child. The expertise of the children’s nurse is built on their ongoing experience in supporting transitions, some may be complex, especially when nursing those with neurological conditions. Myriad of tools are available to measure various elements along a transition pathway, including readiness status indicators, self-management and independence scales, abilities profiles, and behaviors questionnaires that can be administered to young people and parents.

Measurement of a process such as transition is important in managing change and driving improvements in how services are delivered. Constructing a “baseline” with incrementally positive numbers associated with progress is beneficial as it produces interval level data, where the difference between two values is meaningful (Langley & McKenna, 2021). However, without a definition that uses ontology to identify the various elements of transitions, there are challenges to measuring an increase or a decline in progress. The TransitionOmeter we constructed attempted to create a structure based on grounded assumptions relating to a pathway that has a start and an end phase. It also aligned capabilities to resources that could be signposted or developed with the young person and their families to match planned actions. We strongly believe that other nurses could use the framework to advance their practice and enhance services for children and carers. The applicability is especially relevant to those who utilize electronic health records and have the means to influence developments and implementation of data driven innovation.

Further research is needed to explore whether the method we used to construct a simple measurement of progression in health transition is indeed relevant and appropriate for other clinical settings. Research is also needed to affirm whether attempting to simplify and amalgamate measurement, using one tool, has more success in embedding itself in practice. It must be acknowledged that transitions are experienced and managed differently, taking account of the location and context of the support that is being offered. For this reason, accepting and adopting different transition theories, from other disciplines, may be appropriate to ensure a holistic approach is used to guide future research.

Considering the premise of a multiple and multi-dimensional transition approach (Jindal-Snape, 2023), nurses working with children and families who transition to adult services should augment measurement of progress with additional elements. These may

include beliefs, cultural heritage and environmental issues that are important not just for planned care but as core pillars for other types of transitions too.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The work was supported by the Burdett Trust for Nursing.

ORCID

Sharon Levy RN, MPhil  <http://orcid.org/0000-0001-6208-6928>

References

- Association for Real Change (ARC) Scotland. (2019). *Principles of good transitions 3*. <https://scottishtransitions.org.uk/7-principles-of-good-transitions>
- Betz, C. L., & Coyne, I. T. (2020). *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions*. Springer. <https://doi.org/10.1007/978-3-030-23384-6>
- Blount, J. P., Hopson, B. D., & Johnston, J. M., et al. (2023). What has changed in pediatric neurosurgical care in spina bifida? A 30-year UAB/Children's of Alabama observational overview. *Child's Nervous System*, 1–14. <https://doi.org/10.1007/s00381-023-05938-9>
- Cohen, S. E., Hooper, S. R., Javalkar, K., Haberman, C., Fenton, N., Lai, H., Mahan, J. D., Massengill, S., Kelly, M., Cantú, G., Medeiros, M., Phillips, A., Sawicki, G., Wood, D., Johnson, M., Benton, M. H., & Ferris, M. (2015). Self-management and transition readiness assessment: Concurrent, predictive and discriminant validation of the STARx questionnaire. *Journal of Pediatric Nursing*, 30(5), 668–676. <https://doi.org/10.1016/j.pedn.2015.05.006>
- Dicianno, B. E., Fairman, A. D., Juengst, S. B., Braun, P. G., & Zabel, T. A. (2010). Using the spina bifida life course model in clinical practice: An interdisciplinary approach. *Pediatric Clinics*, 57(4), 945–957. <https://doi.org/10.1016/j.pcl.2010.07.014>
- The Duffley Partnership. (2023). *Transitions to adulthood for disabled young people: Literature review prepared for the Scottish government*.
- Ferris, M. E., Harward, D. H., Bickford, K., Layton, J. B., Ferris, M. T., Hogan, S. L., Gipson, D. S., McCoy, L. P., Hooper, S. R. (2012). A clinical tool to measure the components of health-care transition from pediatric care to adult care: The UNC TRxANSITION scale. *Renal Failure*, 34(6), 744–753. <https://doi.org/10.3109/0886022X.2012.678171>
- Gioia, G. A., & Isquith, P. K. (2011). Behavior rating inventory for executive functions. In J. S. Kreutzer, J. DeLuca, & B. Caplan (Eds.), *Encyclopedia of clinical neuropsychology*. Springer. https://doi.org/10.1007/978-0-387-79948-3_1881.
- Haley, S. M., Coster, W. J., Dumas, H. M., Fragala-Pinkham, M. A., Kramer, J., Ni, P., Tian, F., Kao, Y.-C., Moed, R., & Ludlow, L. H. (2011). Accuracy and precision of the pediatric evaluation of disability inventory computer-adaptive tests (PEDI-CAT). *Developmental Medicine & Child Neurology*, 53(12), 1100–1106. <https://doi.org/10.1111/j.1469-8749.2011.04107.x>
- Hart, L. C., Pollock, M., Brown, A., Shah, N., Chung, R. J., Sloane, R., & Maslow, G. R. (2019). Where did they go? Tracking young adult follow-up during the transition from pediatric to adult-oriented care. *Clinical Pediatrics*, 58(11–12), 1277–1283. <https://doi.org/10.1177/0009922819852980>
- Holmbeck, G. N., Kritikos, T. K., Stern, A., Ridosh, M., & Friedman, C. V. (2021). The transition to adult health care in youth with spina bifida: Theory, measurement, and interventions. *Journal of Nursing Scholarship*, 53(2), 198–207. <https://doi.org/10.1111/jnu.12626>

- Jacobson, L. A., Tarazi, R. A., McCurdy, M. D., Schultz, S., Levey, E., Mahone, E. M., & Zabel, T. A. (2013). The Kennedy Krieger independence scales–spina bifida version: A measure of executive components of self-management. *Rehabilitation Psychology, 58*(1), 98. <https://doi.org/10.1037/a0031555>
- Jindal-Snape, D. (2023). Multiple and multi-dimensional educational and life transitions: Conceptualization, theorization and XII pillars of transitions. In R. J. Tierney, F. Rizvi, & K. Erkican (Eds.), *International encyclopedia of education* (4th ed. Vol. 6, pp. 530–543). Elsevier. <https://dx.doi.org/10.1016/B978-0-12-818630-5.14060-6>
- Jindal-Snape, D., Johnston, B., Pringle, J., Kelly, T. B., Scott, R., Gold, L., & Dempsey, R. (2019). Multiple and multidimensional life transitions in the context of life-limiting health conditions: Longitudinal study focussing on perspectives of young adults, families and professionals. *BMC Palliative Care, 18*(1), 1–12. <https://doi.org/10.1186/s12904-019-0414-9>
- Langley, P. C., & McKenna, S. P. (2021). Fundamental measurement: The need fulfilment quality of life (N-QOL) measure. *INNOVATIONS in Pharmacy, 12*(2), 6. <https://doi.org/10.24926/iip.v12i2.3798>
- Levy, S., Farley, S. C., & Campbell, I. (2024). Collecting resilience points for a smooth transition to adult healthcare services: Co-creating a playful resource for Spina Bifida. *Health Care Transitions, 2*, 100036. <https://doi.org/10.1016/j.hctj.2023.100036>
- Levy, S., Wynd, A. H., & Carachi, R. (2014). Transition into adult healthcare services in Scotland: Findings from a study concerning service users at the Scottish Spina Bifida association. *Scottish Medical Journal, 59*(4), 209–213. <https://doi.org/10.1177/0036933014556200>
- Logan, L. R., Sawin, K. J., Bellin, M. H., Brei, T., & Woodward, J. (2020). Self-management and independence guidelines for the care of people with spina bifida. *Journal of Pediatric Rehabilitation Medicine, 13*(4), 583–600. <https://doi.org/10.3233/PRM-200734>
- Nagra, A., McGinnity, P. M., Davis, N., & Salmon, A. P. (2015). Implementing transition: Ready steady go. *Archives of Disease in Childhood-Education and Practice, 100*(6), 313–320. <https://doi.org/10.1136/archdischild-2014-307423>
- Oakland, T., & Harrison, P. L. (2011). *Adaptive behavior assessment system-II: Clinical use and interpretation*. Academic Press.
- Paez, A. (2017). Gray literature: An important resource in systematic reviews. *Journal of Evidence-Based Medicine, 10*(3), 233–240. <https://doi.org/10.1111/jebm.12266>
- Psihogios, A. M., Kolbuck, V., & Holmbeck, G. N. (2015). Condition self-management in pediatric spina bifida: A longitudinal investigation of medical adherence, responsibility-sharing, and independence skills. *Journal of Pediatric Psychology, 40*(8), 790–803. <https://doi.org/10.1093/jpepsy/jsv044>
- Rethlefsen, M. L., Kirtley, S., Waffenschmidt, S., Ayala, A. P., Moher, D., Page, M. J., Koffel, J. B., Blunt, H., Brigham, T., Chang, S., Clark, J., Conway, A., Couban, R., de Kock, S., Farrah, K., Fehrmann, P., Foster, M., Fowler, S. A. . . . Wright, K. (2021). PRISMA-S: An extension to the PRISMA statement for reporting literature searches in systematic reviews. *Systematic Reviews, 10*(1), 1–19. <https://doi.org/10.1186/s13643-020-01542-z>
- Sawin, K. J., Heffelfinger, A., Cashin, S. E., & Brei, T. J. (2018). The development of the adolescent/young adult self-management and independence scale II: Psychometric data. *Journal of Pediatric Rehabilitation Medicine, 11*(4), 311–322. <https://doi.org/10.3233/PRM-170479>
- Sawin, K. J., Margolis, R., MacFarlane Bookman, J. R., Bellin, M. H., Romeiser Logan, L., Woodward, J., & Timothy, J. (2020). Brei analysis of self-management and transition readiness instruments for clinic practice. In C. L. Betz & I. T. Coyne (Eds.), *Transition from pediatric to adult healthcare services for adolescents and young adults with long-term conditions: An International Perspective on Nurses Roles and Interventions* (pp. 71–109). Springer nature Publishing. <https://doi.org/10.1007/978-3-030-23384-6>
- Schumacher, K. L., & Meleis, A. (1994). Transitions: A central concept in nursing. *Image: The Journal of Nursing Scholarship, 26*(2), 119–127. <https://doi.org/10.1111/j.1547-5069.1994.tb00929.x>
- Scottish Government. (2023). *Transitions to adulthood strategy: Statement of intent*. Scottish Government.

- Stehouwer, N., Edge, P., Park, B., Piccone, C., & Little, J. (2017). Acute pain in adolescents and young adults with sickle cell disease: Delayed and increased opioid dosing following transition to adult care. *American Journal of Hematology*, 92(4), E40–E42. <https://doi.org/10.1002/ajh.24647>
- Stern, A. R., Winning, A. M., Rausch, J. R., & Holmbeck, G. N. (2021). Medical responsibility growth in youth with spina bifida: Neuropsychological and parenting predictors. *Health Psychology*, 40(10), 692. <https://doi.org/10.1037/hea0001089>
- Williams, T. S., Sherman, E. M. S., Dunseith, C., Mah, J. K., Blackman, M., Latter, J., Mohamed, I., Slick, D. J., & Thornton, N. (2011). Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. *International Journal of Child and Adolescent Health*, 3(4), 527–535.
- Wood, D., Rocque, B., Hopson, B., Barnes, K., & Johnson, K. R. (2019). Transition Readiness Assessment Questionnaire Spina Bifida (TRAQ-SB) specific module and its association with clinical outcomes among youth and young adults with spina bifida. *Journal of Pediatric Rehabilitation Medicine*, 12(4), 405–413. <https://doi.org/10.3233/PRM-180595>
- Wright, A. E., Robb, J., & Shearer, M. C. (2016). Transition from paediatric to adult health services in Scotland for young people with cerebral palsy. *Journal of Child Health Care*, 20(2), 205–213. <https://doi.org/10.1177/1367493514564632>
- Wysocki, T., & Gavin, L. (2006). Paternal involvement in the management of pediatric chronic diseases: Associations with adherence, quality of life, and health status. *Journal of Pediatric Psychology*, 31(5), 501–511. <https://doi.org/10.1093/jpepsy/jsj042>
- Yeung, E., Kay, J., Roosevelt, G. E., Brandon, M., & Yetman, A. T. (2008). Lapse of care as a predictor for morbidity in adults with congenital heart disease. *International Journal of Cardiology*, 125(1), 62–65. <https://doi.org/10.1016/j.ijcard.2007.02.023>