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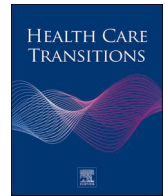
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# Collecting resilience points for a smooth transition to adult healthcare services: Co-creating a playful resource for Spina Bifida

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## ABSTRACT

**Background:** The transition of young people with a disability or a chronic health condition, from paediatric to adult-focused health and social care services, in Scotland, is known to be difficult. There is a significant body of evidence to suggest that a transition should start early, be holistic and inclusive, as well as structured to build essential capabilities and promote resilience. The nurse-led project, reported here, created a playful mechanism for meaningful interaction between young people, families and healthcare professionals.

**Methodology:** Using participatory design as a framework to support development of a collaborative boardgame, guided ways to develop a 'sense of coherence'. The ecological framing of resilience shaped the way captured lived experience, of adults with spina bifida who transitioned to adult care, was used to support developments. Experiential learning guided the co-creation of a playful resource on a journey through transition that could be used by families as well as healthcare students and professionals. We also explored ways to enhance a 'Sense of Coherence' and build resilience through serious game design.

**Results:** In this nurse-led project we jointly crafted and tested a transition game that is easily accessible, inclusive and sufficiently adaptable to fit different settings, communities and cultures. The open licence enables others to freely use and adapt this game so it could be further used, tested and validated.

## 1. Introduction: setting the scene - transition and resilience

The transition of young people with a disability or a chronic health condition, from paediatric to adult-focused health and social care services<sup>24</sup> is known to be difficult. Using a medical gaze, those with spina bifida and/or hydrocephalus (SB/H) are often perceived as complex medical presentations with a range of physical disabilities and for some, limitations in cognitive and communication skills. These attributes and attitudes increase the challenges young people face when transitioning into the adult healthcare system. For the young person it may be frightening to use a new system with a myriad of new health and social care providers they have never seen before. For example, a young person will experience a movement away from one medical consultant and a small group of nursing staff in one dedicated paediatric hospital, to be seen by several consultants and a variety of nurses across different hospitals in adult services. For the parents it can be challenging to 'let go' and give their child the agency to independently navigate access to health and care services. For staff in the paediatric hospital, it is saying goodbye after many years of caring and supporting a family. Staff in the

adult service will see the person sporadically and often only when or after they experienced a crisis or a marked deterioration in their health status. These are the experiences articulated through engaging with service users as well as providers of care services for young people with Spina Bifida and their families in Scotland<sup>19</sup>.

It is argued that the role of the nurse in transitional care is fundamental to the quality of that process<sup>12</sup>, and there is a significant body of evidence and a plethora of global guidance to suggest that such a transition should start early<sup>2</sup>. Moreover, the transition process should also be holistic and inclusive, as well as structured to build essential capabilities and promote resilience<sup>6</sup>. The term 'resilience' has received heightened attention in recent years, aligned to the global covid 19 pandemic (2020–2022). Resilience is often associated with desirable individual traits such as being able to 'cope' with stress, adjust, and with successfully adapting to changes. Ahern<sup>1</sup> affirms that adolescent resilience is a concept of enormous utility in nursing, noting it has been studied chiefly in relation to times of transition that are accompanied by stress.

The link between stress and health, through the lens of resilience is the focus of the Salutogenic theory, developed to understand how people

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manage stress and stay well<sup>4</sup>. Antonovski's earlier work affirms his argument that the focus on risks, ill health, and disease should shift onto peoples' resources and capacity to create health and wellness<sup>3</sup>. The Salutogenic theory holds 'coherence' as a key concept and conceives of the world as having chaos and change as a normal state of life<sup>14</sup>. Coherence acts as an alternative to the chaos, and the use of a Sense of Coherence (SOC), for young people, was studied extensively<sup>8</sup>. Personal and systemic (i.e., family and community) SOC was shown to be an important resource for coping with a wide variety of stressful situations, especially at an age where the path to maturity and normative adulthood is being sought.

When considering interventions to enhance SOC, whilst transitioning onto adult care services, core health promotion principles should also guide developments. These should be focused on action, promote empowerment, be participatory in nature, holistic, equitable and sustainable<sup>22</sup>. It is also argued that an early intervention approach, which continues past adolescence into early adulthood is needed<sup>5</sup>. These were the guiding principles that informed the co-created transition boardgame: The Young Heroes Team. We stress that our desire to build resilience for young people was not an attempt to 'fix deficits' as often propelled by a medical model of disability. Rather, we concur with the notion that attainment of resilience is strongly influenced by wider social contextual determinants<sup>27</sup>.

An ecological framing of resilience, as suggested by Ungar<sup>25</sup>, fits well the requirement to consider transition of young people in the context of their families and their wider support network that includes nursing care. Ungar definition of resilience reads: "...the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of well-being, and a condition of the individual's family, community and culture to provide these health resources and experiences in culturally meaningful ways" (pp 225).

Adopting this prism enabled a nurse-led team to successfully co-design a collaborative boardgame for young people, their carers and healthcare professionals. The aim of the game is to collect resilience points along a journey and thus highlighting for players, the role of resilience in a successful transition journey. The ultimate outcome was to create a playful path through transition, with hurdles and opportunities for progression and learning, situated in lived experience of the game's co-designers from across Scotland.

### 1.1. Serious games, young people and co-design

Serious games are most often used as a pedagogical approach in nurse education where they appear to be effective for improving knowledge, skills, and satisfaction<sup>16</sup>. The first definition of a serious game, in 1970, identified games that "have an explicit and carefully thought out educational purpose and are not intended to be played primarily for amusement"<sup>28</sup>.

Kaufman, Flanagan, and Seidman<sup>18</sup> found that games which seek to impart core knowledge in an explicit fashion are less successful than those that take a more "stealthy" approach by anchoring persuasive messages within a game's content or context. These authors provided a model which aims to bypass players' psychological barriers to try to foster a more positive or receptive mindset for players with three distinct "Embedded Design" elements:

- (1) Intermixing: balancing "on-message content" being the information or message that the game aims to impart and "off-message content" used to distract or ease the player into the game's message or aims;
- (2) Obfuscating: using framing devices or genres that divert expectations or focus away from the game's persuasive intent. The choice to frame Young Heroes as a collaborative game of heroes was deliberate to bring in elements of fun and fantasy to provide levity and a safe space for players alongside the more serious elements of the game.; and

- (3) Distancing: employing fiction and metaphor to increase the psychological gap between players' identities and beliefs and the game's characters and persuasive content. The players are working together to solve problems faced by the characters in the game, not themselves. This distancing is an important factor in the design.

This model and the guidelines for serious games design for children<sup>26</sup> guided our approach to creating the boardgame with a group of young adults and their carers, who recently completed the transition process. The use of a participatory design approach<sup>7</sup> to co-design a transition game, was anchored in the belief that involving end users and stakeholders in the process itself, delivers relevant and needed outputs. It also fits a person-centred practice philosophy, which promotes a desired sense of empowerment through participation. This drive for collective creativity<sup>23</sup>, was tailored to suit the context of young people with spina bifida and based on an empathic understanding of the people involved. We were also guided by emerging principles as reported by Raman and French<sup>21</sup> and articulated ways of enabling meaningful participation of young people in co-design efforts.

Serious games have been used as an intervention to support children and young people with chronic disease for a myriad of conditions<sup>17</sup> and for improving knowledge and self-management of ill health<sup>10</sup>. A most recent study<sup>13</sup> found that serious games are increasingly being used for a wide range of health conditions but that the focus is shifting towards the use of mobile and digital platforms as well as virtual reality, and machine learning to personalize and adapt interventions. The game we designed was specifically aimed to be low-tech to enable anyone with access to the Internet and a printer to download the free file, print the black and white boardgame and play it immediately, wherever they are.

## 2. Materials and methods

Creating a game that accurately reflects the experiences of young people and their families, transitioning from child to adult health services in Scotland, has been core to the entire design process. To that end, we collaborated with a group of individuals who were able to reflect, articulate and share their specific challenges and learning from experiencing the transition journey themselves. Engaging participants with the aim of sharing their lived experience, online, necessitated careful consideration to the tools that were used and the visual storytelling methods we utilised. Three one-hour workshops were conducted on consecutive weekends with a core group of volunteers (n = 10). These were individuals who accepted an invite shared on a closed Facebook group managed by Spina Bifida Hydrocephalus Scotland (SBH Scotland).

The convenience sample consisted of dyads (parent and young person) who reside in the same house as well as single participants (young persons) living independently. Running the workshop at the weekend enabled more people to attend and having it online offered an opportunity for people from across Scotland to take part. Informed consent for participation was obtained and the privacy rights of participants was observed at all times. No incentive was offered but people were generous with their time, as well as, with the offer of sharing advice to others who are following in their footsteps.

The first two workshops focused on sharing stories about experiences, as well as, examples of real-life hurdles encountered along the transition pathway. We encouraged a natural flow of the discussion and after a short introduction asked participants to introduce themselves and share their story, whilst enabling all participants to have an opportunity to be heard. Discussions also considered what types of games the group felt would be the most engaging and useful for young people and families navigating out of paediatric and onto adult-focused services. The fact that we only had one individual who dropped out from the group at this stage demonstrated that the sessions were engaging and fun. Moreover, participants commented on the fact that this was an

opportunity to meet new people out with their locality in a similar situation from different parts of Scotland.

Following the first two workshops, participants expressed a firm preference for the game to be co-operative, with all players working together towards a common goal. It also became clear that designing the game to focus on discussions and reflections would best achieve the goals of imparting the experiences and knowledge shared by participants. Taking these factors into account, and following the embedded design principles<sup>18</sup>, the draft game was taking inspiration from the open licensed game PlayDecide<sup>15</sup>. It is a discussion game, with a role-playing component, used for players to talk in a simple and effective way about potential challenges and changes they may experience in their future. The game also combined the discussion elements alongside deck building and storytelling mechanics. Deck building is a common card game approach where players aim to collect and add specific cards to a visible 'deck' in order to achieve specific goals and outcomes. The Young Heroes setup has a deck from which each player draws 2 cards to read out and discuss with other players. Together they agree on which journey deck to place cards so that all 3 heroes reach the shared goal.

As can be seen in the appendix, five types of cards were created to encompass the range of experiences and helpful insights provided by participants:

- **Character Cards:** The fictional character that players are building the deck of experiences around. All three characters must achieve 15 resilience points for players to win the game.
- **Life Events:** Big change life events (e.g. a new job or learning opportunity) that can bring about positive or negative effects + or - 5 points
- **Buddy:** A card that simulates a friend providing help, advice, or support to the character. +3 points
- **Hurdle:** Obstacles and incidents that make the transition harder. -2 points
- **Star:** Positive events, tools, or services that make transition easier. +2 points

A first draft of the game was created using Padlet, an online collaborative noticeboard, and then demonstrated during the third workshop. Participants were pleased with the shape and content of the game, providing feedback on additional experiences for each of the card types. Implementing all the co-design elements and feedback from the workshops, our game designer and graphic designer refined the draft to create a printable PDF document including an overview of the game, how to play it, and the cards themselves.

### 2.1. Playtesting and refining the game design

Playtesting is an important element in game design as it is how designers check to ensure that the instructions make sense and are playable, that there are no flaws in the mechanics, and that players interact and experience the game in the intended way. Four playtest sessions were scheduled over a three-month period. The first playtest was scheduled with Scottish health practitioners, as part of the game design intention included communicating the transition experience from the perspective of a young person going through the process to the healthcare team that support them.

Covid-19 restrictions meant the playtests all needed to occur remotely and online. In order to facilitate this, copies of the boardgame with the cards already cut out and ready for play were sent directly to each playtest volunteer. The playtest was conducted online with each player pulling cards from their own decks, discussing them with other players and then collaboratively deciding which character deck to play the card. Feedback from the healthcare team was particularly positive around the discussion element of the game where players are encouraged to discuss how the events outlined in the cards impact on the characters and which characters were best placed, with resilience points,

buddy, or star cards, to handle or benefit from the cards.

Following the play testing, the game design was updated, and a new version sent out to the next testers: a few young people and their families. Each play tester came to the game with no previous knowledge or view of earlier versions. This was repeated each time providing valuable insight and feedback from testers and their families on elements of the game for fine tuning and improvement.

Areas of refinement to the design focused on creating clear and concise instructions in plain English to communicate the game play and rules, and intermixing, obfuscating and distancing elements that integrated the "Embedded Design" model. This included further implementation of additional story elements to depict a young hero adventuring out into the adult world of health and social care. Development continued to focus on infusing fun and playfulness to the game play, while also providing fiction to increase the psychological distance between the players and the game characters. Card content was also edited and updated to provide a mixed balance of "on-message" and "off-message" content, for example some cards focused on fun elements such as decoration, while others tackled more serious and potentially anxiety inducing scenarios. The player characters were further defined as a team of three young heroes setting off on adventures to build their resilience. The 'No hero left behind' element of the game binds the cooperative element, requiring that all players work together to help all three characters of the hero team achieve the required number of resilience points for the game to resolve.

### 2.2. Accessibility and inclusive design

The original set output for the project was the design of an engaging game, focusing on spina bifida, that is accessible, inclusive, and reusable. Its aim was to support young people, families and healthcare professionals involved in the transition from paediatric to adult-focused services. A number of steps were included in the design and graphic elements of the game to ensure that the game strives to be as accessible and inclusive as possible, including:

- Designed as an easily downloadable PDF pile for easy print and play by anyone with access to the internet and a printer.
- An accessible font was purchased for the game text and cards in order to increase accessibility and the design has used a grayscale colour to reduce printing costs. The use of a greyscale was found by our play testers to not affect their enjoyment of the game as they enjoyed the graphic style and illustration elements.
- The characters and their illustrations were designed with an eye towards gender, race, and ability inclusion and players can choose from multiple hero character options to build their team of three heroes for game play.
- Blank cards of each type of card, including hero character cards, have been included on the print and play document with accompanying text encouraging players to create and draw their own hero characters, and their own hurdles, star, buddy, and life event cards to reflect their own experiences.
- Instructions meet accessibility requirements in line with UK guidelines in terms of font and spacing.

Re-usability and adaptation by young people and their healthcare team is embedded through the application of a Creative Commons Attribution Share-Alike licence. This licence allows anyone to remix, adapt, edit, translate and re-use the game according to their needs so long as anything created from the game is clearly attributed to the original creators and also made freely available under a Share-Alike licence for others to continue to benefit from and use.

## 3. Application

While there are a growing number of tools, models and frameworks

to prepare young people and families, there remain gaps in training of professionals in transition of care, including specific content within undergraduate and postgraduate medical education<sup>9</sup>. We therefore see the applicability of using the game for both practice and training/education.

We suggest that the Young Heroes game could augment current interventions and enhance efforts to establish a sense of coherence. Following a playful interaction, encouraging discussion and exchange of ideas, participants may pick up a card that suggests the dedicated consultant whom they know very well is about to retire. When this scenario was explored in one of our playtests the initial reaction was anxiety for the young person, which was then alleviated through purposeful discussion as a family. Within the rules of the game, players had to explore ways to mitigate the impact of such a hurdle card, which includes the deduction of 2 resilience points, by exchanging resilience points they gained elsewhere on their path. For example: a buddy card, where a friend is offering help, advice, or support to the character is worth 3 points, which could be presented as a mitigation strategy. A star card, e.g., 'supported by a multidisciplinary team' is worth 2 points and can easily outweigh the hurdle enabling the Young Hero Team to progress. The blank cards can be used to tailor the games to a specific situation and playing the game in set intervals may demonstrate progress, remind families about planned actions or questions that needed answers or seek and share information with others within their social circle.

Using the game as an education tool with students could help them to understand the lived experience of young people and parents affected by a chronic health condition such as Spina Bifida and/or Hydrocephalus. Using games for knowledge gain and skills acquisition provides a means for students to practice and hone capabilities in a realistic and safe manner<sup>20</sup>. As a pedagogical approach gamification offers an innovative and engaging teaching strategy that, apart from improvement of learning, are also proven to enhance creativity and critical thinking<sup>29</sup>. The terms gamification and simulation are often aligned to the term serious games and are often used in the context of resolving some of the challenges in training and education of aspiring professionals. An example would be using virtual reality to address the growing number of learners in busy clinical settings that experience staff shortages and lack of suitable mentors for students.

The Young Heroes game could also be used to aid a medical intervention, which may be designed to enhance self-care. If there was time to 'play', a clinician, a young person and their family could explore the planned pathway through the game, as part of the consultation or thereafter by adding the proposed intervention as a card and including it in a game. If that was taking place in the clinic, questions and concerns could be addressed immediately whereas if done at home, a list of questions could aid a follow-on consultation to aid shared decision making.

#### 4. Discussion

Transitioning from paediatric to adult care is known to be a challenging process for young people with spina bifida and/or hydrocephalus. This process involves not only the transfer of medical care but also the development of skills necessary for self-management of the condition and increased independence. It also requires the development of capabilities and strategies to overcome perceived challenges and the skills or resilience that supports a Sense of Coherence. The literature that explores strategies and interventions to support transition in this population<sup>11</sup> identifies a number of structured interventions including:

- proactive transition planning that starts early and involves the collaboration of the paediatric and adult healthcare teams, the young person and their family, and in some settings a dedicated transition coordinator (or 'named person'); and

- dedicated transition training preparation and programmes that offer a structured curricula focusing on self-care capabilities, effective communication and social interactions as well as assistance to explore educational and vocational opportunities.

Evidence indicates that serious games are used as a therapeutic tool to support the care of children with a range of chronic conditions. Evaluation of such interventions are often focused on effectiveness and outcome for a specific disease or condition where, for example, a notable efficacy in managing asthma and diabetes was found<sup>17</sup>. Another example for the effectiveness of using games for children with Autism Spectrum Disorder<sup>29</sup> found improvement in children's comprehension and perception of others' emotional expressions. The therapeutic theoretical underpinning on which these games were designed varies, with some focusing on emotional development whilst others create games that aligned to cognitive developments. The use of pedagogical theories such as Behaviourism and Constructivism to design gameplay rules, interaction method as well as reward design often mirror the developers' background and rarely such developments are co-produced with end users, as was the case in co-creating the Young Heroes game.

#### 5. Conclusion

Our nurse-led project brought together key stakeholders to design and test a unique game that could be used for a range of users, environments and purposes. We now seek others who can use, refine and enhance this game to support the process of enabling young people, with a range of chronic conditions, to successfully transition from child-centred to adult-orientated health and care systems.

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#### Ethical statement

We have included a statement within the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects was and must always be observed.

#### CRedit authorship contribution statement

**Levy Sharon:** Conceptualization, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing. **Farley Stephanie (Charlie):** Data curation, Methodology, Resources, Validation, Visualization, Writing – original draft, Writing – review & editing. **Campbell Iona:** Formal analysis, Project administration, Supervision, Writing – review & editing.

#### Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Sharon Levy reports financial support was provided by Burdett Trust for Nursing.

#### Data availability

The authors do not have permission to share data.

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## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2023.100036](https://doi.org/10.1016/j.hctj.2023.100036).

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