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Designing healthcare interventions: Insights from a participatory co-design approach

RESEARCH INSIGHT

Janine Noorloos[1], Jaspreet Randhawa[2], Peola Ellis[3], Geil Astorga[3], Fairuz Karim[3]

1. Department of Population Medicine, Ontario Veterinary College, University of Guelph, Guelph, ON, Canada
2. Harvard Medical School, Harvard University, Cambridge, MA, USA
3. Department of Laboratory Medicine and Pathobiology, University of Toronto, Toronto, ON, Canada

SUMMARY

We used a participatory co-design approach to improve healthcare transitions for youth with sickle cell disease (SCD). The key outcome was the development of an accredited digital educational module for healthcare providers. Lessons learned included the following: 1) Responsive design should be shaped by lived experience, not predetermined solutions; 2) Participant backgrounds influence intervention outcomes; 3) Provider education is a key strategy to address systemic challenges; 4) Provider-focused interventions should still prioritise patient needs; and 5) Collaboration is essential for impact and dissemination. The insights gained when addressing SCD care and transition experiences may be useful when designing interventions for other complex healthcare challenges.

Key Words

sickle cell disease; youth; transitions; human-centred design; participatory co-design

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Corresponding Author: Janine Noorloos (noorlooj@uoguelph.ca): Department of Population Medicine, Ontario Veterinary College, University of Guelph, Guelph, ON, Canada

INTRODUCTION

Sickle cell disease (SCD) is a haemoglobinopathy that primarily affects red blood cells, leading to various life-threatening complications, including vaso-occlusive pain crises.[1] In the United States, data show that 93.4 per cent of people affected by the condition between 2016 and 2018 were among the Black population.[2] There are limited ethnic and racial data in Canada; however, available data show approximately 6,500 individuals live with SCD, half of whom reside in Ontario.[3] The average age of people with SCD in Ontario is 24 years, and most complications arise in young adulthood.[3] As these individuals transition from paediatric to adult healthcare services, significant challenges emerge, particularly at the critical age of 18, which marks the transitionary point in the healthcare system.[4] While formal transition programmes exist at institutions like the Hospital for Sick Children in Toronto, such programs are not universally available across Ontario. This study aimed to improve transition readiness using a human-centred design approach for youth living with SCD, designing an intervention that addresses their unique needs during this period.

SUMMARY

The key outcome of our research was the development of a co-designed digital educational module framework.[5] Our research team then used the research and framework to create and publish an accredited continuing education module for healthcare providers. The "Successful Transitions for Adolescents and Young Adults with Sickle Cell Disease" module is available through the Sickle Cell Disease Education Program for Healthcare Professionals offered through the Sickle Cell Awareness Group of Ontario (SCAGO).[6] Topics and lessons in the module include defining transition, barriers faced by youth, strategies to support youth, and a reflective case study. The module is a form of continuing medical education that is useful for many healthcare providers and is certified by the College of Family Physicians of Canada for Mainpro+ credits.

LESSONS LEARNED

Our experience, from the research to the knowledge translation phase, yielded five important insights relevant to researchers, designers, healthcare providers, and patients: 1) Responsive design should be shaped by lived experience, not predetermined solutions; 2) Participant backgrounds influence intervention outcomes; 3) Provider education is a key strategy to address systemic healthcare challenges; 4) Provider-focused interventions should still prioritise patient needs; and 5) Collaboration is essential for impact and dissemination.

Responsive design requires lived experience, not predetermined solutions

Design is a valuable problem-solving method in healthcare, encompassing not only physical products but also processes, environments, and educational content. Before starting the design process, we envisioned a mobile app for youth to track and share their health information. However, we opted for a participatory co-design approach, meaning we had a pre-specified problem but did not bring forward our idea of an app as a solution.[7] Participants created personas, completed a "5 Whys" activity to identify root causes, and ideated with "How might we" questions to conceptualise potential interventions. Through this process, participants generated many ideas but ultimately determined, using a feasibility and desirability matrix, that a digital module focused on provider education would be the most impactful intervention.[5] This process highlights the importance of employing a human-centred design approach. Rather than assume a solution, engaging individuals with lived experience of SCD in Ontario throughout the entire process directly informed and shaped the final intervention.

Participants' backgrounds influence intervention outcomes

The composition of a participant group can significantly influence the outcomes of a participatory design process. Seven participants were involved in the design sessions. Three were adults with lived experience of SCD who had previously navigated the transition from paediatric to adult care. Another three were healthcare providers (in nursing or social work) who also had lived experience of SCD and had themselves gone through the healthcare transition process. The final participant was a paediatric nurse practitioner who did not have lived experience of SCD but had professional experience caring for patients with SCD, including those transitioning into adult care. In this group, 57 per cent (4/7) of participants were healthcare providers. The emphasis on healthcare provider education as the preferred intervention likely reflected the participants' shared interest in improving care from a provider perspective. It is important to recognise, however, that the transition needs and priorities of current youth with SCD may differ from those of adults reflecting on their past experiences.

Balancing immediate impact with systemic challenges

Many participants reflected on the lack of adequate SCD knowledge among healthcare providers, particularly in emergency departments where opioids are commonly prescribed. They also described experiences of racial bias, further exacerbating their negative interactions with the healthcare system.[5] In designing interventions, discussions primarily focused on changes that healthcare providers could make rather than changes patients need to create themselves. This collective direction aligned with the participants' belief that education is the most effective immediate intervention to improve care and outcomes for SCD patients. While policy changes in Ontario, such as the recent quality standard, *Sickle Cell Disease: Care for People of All Ages*, are needed, there has also been discourse on the limitations of health policymaking in addressing institutional inequity and neglect for SCD patients.[8] The educational module developed following this study offers a more direct, tangible, and immediate means of addressing current gaps in care.

Patient-centred design for provider-focused interventions

Although the beneficiaries of the intervention were healthcare providers, the participatory design process kept patients' needs at the forefront. By consistently including patients in every step, from ideation to content development, we ensured that the module's final product addressed patients' experiences and challenges. The module includes lessons and case studies designed to prompt reflection on improving healthcare practices, ensuring the intervention remains human-centred.

Collaboration and partnerships for impact

Successful health design requires collaboration across multiple stakeholders. Throughout this project, we engaged with various individuals and organisations to ensure the intervention and knowledge dissemination strategies were relevant and impactful. For example, our partnership with the Sickle Cell Awareness Group of Ontario (SCAGO) was crucial in disseminating the final product, making the educational module accessible to healthcare providers across Canada. Partnerships like these are essential for ensuring that health interventions reach the broader population and many audiences, especially in regions with limited local transition programmes.

Moving forward

This research highlights the importance of participatory design in developing health interventions that are truly responsive to the needs of those affected by SCD. By focusing on improving healthcare provider education, we aimed to facilitate smoother transitions for youth with SCD into adult care. The module developed through this process now serves as a resource for providers across Ontario, contributing to a more informed, empathetic approach to SCD care. This research demonstrates the power of collaboration and human-centred design in addressing complex healthcare challenges.

CLINICIAN INSIGHT

Research clearly supports continuity of care as an effective model to support young people with complex health conditions throughout their healthcare journey.[1] However, there are significant gaps in support for young people transitioning into adult healthcare services, with those at highest risk often having the lowest engagement. The Participatory Action Research (PAR) model[2] is an excellent framework for this research as it is predicated on the direct involvement and empowerment of end users, in partnership with researchers, clinicians, and care providers. A further strength of PAR is that changes can be made in real time, based on direct feedback from stakeholders.

This research team is to be applauded for including all potential key stakeholders in the exploratory phase of this study and for empowering young people to engage in optimising the healthcare transitional journeys of others with SCD. All health professionals working to support those with SCD should be encouraged to complete the resultant accredited educational module that seeks to better support young people making the transition from youth to adult healthcare services. The authors should consider building this methodology into an evidence-based Model of Care that is transferable across other transitional healthcare services.

Prof Alexandra McManus, PhD, MPH, PGDipPH, BSc HP/H.Biol, GAICD, MAIFST, AFACRS
Director, McManus R&D Consulting
Adjunct Professor, Faculty Health Sciences, School of Population Health, Curtin University, Perth, Australia
Adjunct Professor, School of Medicine, University of Notre Dame, Sydney, Australia

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The coauthors made the following contributions:

- JN conceptualised, planned and conducted the study, participated in the analysis, contributed to module development, and drafted the manuscript.
- JR, PE, GA, and FK conceptualised, planned, and conducted the study, participated in the analysis, contributed to module development, and reviewed the manuscript.

PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

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ETHICS COMMITTEE APPROVAL

The University of Toronto granted research ethics approval for this study (REB# 43907).