Exploring Digital Psychosocial Follow-up for Survivors of Childhood Critical Illness

Marte Hoff Hagen
Norwegian University of Science and Technology, Department of Computer Science, Norway marte.h.hagen@ntnu.no

Abstract
This extended abstract describes the plan and status of a PhD project using a design science research approach to explore how to design digital psychosocial follow-up for survivors of childhood critical illness.

Keywords
Childhood critical illness, Long-term follow-up care, Psychosocial, Digitalization, Design science research

1 INTRODUCTION

The risk of long-term negative psychosocial consequences may be increased by intensive treatment procedures and hospitalization in childhood [1 - 3]. This risk applies especially to survivors of Anorectal malformations and Hirschsprung's disease [4 - 7], two congenital colorectal defects which require surgery and intensive treatment procedures [7, 8]. Research indicates that information technology solutions provide beneficial psychosocial outcomes to survivors of critical illness (e.g., [9, 10]), but these examples target only childhood cancer survivors. Thus, this PhD project aims to explore designing solutions for digital psychosocial follow-up for survivors of childhood critical illness in general, not only childhood cancer survivors.

2 METHODS

This PhD project uses a design science research approach [11] to investigate how an innovative information technology solution for digital psychosocial follow-up for survivors of childhood critical illness should be designed according to the current knowledge and the different stakeholders' needs. A specific solution will be developed for the target group identified as child survivors of Anorectal malformations and Hirschsprung's disease to create general design principles regarding digital psychosocial follow-up for all different survivors of childhood critical illness.

The first step of the design science research approach is to identify and motivate the problem. To identify the problem, expert interviews [12] were conducted with six health professionals at a Norwegian hospital with relevant knowledge of the current psychosocial follow-up for survivors of childhood critical illness at the hospital. The qualitative data gained in this sub-study were analyzed through thematic analysis [13].

3 RESULTS

The expert interviews resulted in a mapping of the current psychosocial follow-up for survivors of childhood critical illness at the Norwegian hospital, presented in Figure 1.

4 DISCUSSION

The expert interview findings demonstrated the importance of considering the affecting factors and technological opportunities and limitations when designing digital psychosocial follow-up for survivors of childhood critical illness. Based on these findings, it was created the following preliminary design principles for the information technology solution of digital psychosocial follow-up for survivors of childhood critical illness:

1. Work toward gender-, culture-, and residence-neutrality.
2. Enables customization to specific medical conditions and age groups.

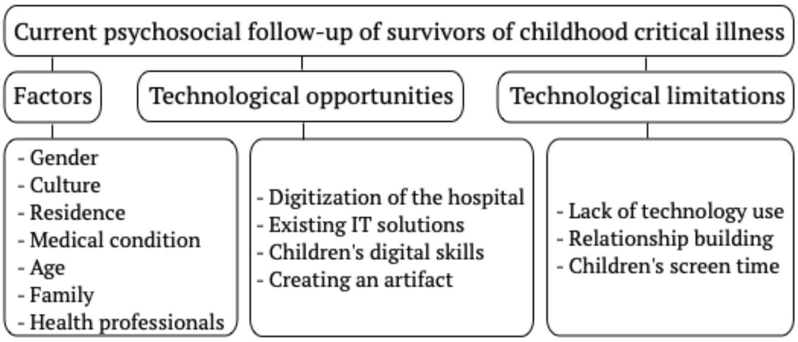

Figure 1 Mapping of the current psychosocial follow-up for survivors of childhood critical illness at the Norwegian hospital.

The 18th Scandinavian Conference on Health informatics, Tromsø, Norway, August 22-24, 2022. Organized by UiT The Arctic University of Norway. Conference Proceedings published by Linköping University Electronic Press at https://doi.org/10.3384/ecp187.

3. Include information sites for family members and health professionals.

4. Exploit the target group's technological opportunities but also consider their technological limitations.

These preliminary design principles will be further explored during the remaining PhD project period. To supplement the principles in a practical context, the next step is conducting a systematic literature review following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement [14] to identify the current existing information technology solutions. Then, a sub-study consisting of interactive workshops with the target group will combine the obtained knowledge to identify the target group's needs for the specific information technology solution. Besides, an interview sub-study with designers and developers in companies and NGOs developing relevant information technology solutions will be conducted to investigate if existing design theory could help them understand these identified needs. Moreover, the findings will be used to develop an artifact contribution - a prototype of an information technology solution for digital psychosocial follow-up for the target group. This prototype will be user-tested in two iterations. The prototype can contribute to the vulnerable children in the target group individually by giving more personalized follow-up improving life quality and socially by providing society with a better solution for survivors of childhood critical illness, reducing the burden on the psychological service. The results from all these sub-studies will finally be used to create the methodological contribution - final design principles regarding digital psychosocial follow-up for survivors of childhood critical illness.

5 REFERENCES

[1] Ekim, A. "The Post-Intensive Care Syndrome in Children" in *Comprehensive Child and Adolescent Nursing* Vol. 43, Issue 1, pp. 15–21. Tylor & Francis 2020. https://doi.org/10.1080/24694193.2018.1520323

[2] Manning, J. C., Hemingway, P., and Redsell, S. A. "Long-term psychosocial impact reported by childhood critical illness survivors: a systematic review" in *Nursing in Critical Care* Vol. 19, Issue 3, pp. 145–156. John Wiley & Son 2014. https://doi.org/10.1111/nicc.12049

[3] Diseth, T. H. "Dissociation following traumatic medical treatment procedures in childhood: A longitudinal follow-up" in *Development and Psychopathology* Vol. 18, Issue 1, pp. 233–251. Cambridge University Press 2006. https://doi.org/10.1017/S0954579406060135

[4] Collins, L., Collis, B., Trajanovska, M., Khanal, R., Hutson, J. M., Teague, W. J., and King, S. K. "Quality of life outcomes in children with Hirschsprung disease" in *Journal of Pediatric Surgery* Vol. 52, Issue 12, pp. 2006–2010. Elsevier 2017. https://doi.org/10.1016/j.jpedsurg.2017.08.043

[5] Grano, C., Aminoff, D., Lucidi, F., and Violani, C. "Long-term disease-specific quality of life in children and adolescent patients with ARM" in *Journal of Pediatric Surgery* Vol. 47, Issue 7, pp. 1317–1322. Elsevier 2012. https://doi.org/10.1016/j.jpedsurg.2012.01.068

[6] Nah, S. A., Ong, C. C. P., Saffari, S. E., Ong, L. Y., Yap, T. L., Low, Y., and Jacobsen, A. S. "Anorectal malformation & Hirschsprung's disease: A cross-sectional comparison of quality of life and bowel function to healthy controls" in *Journal of Pediatric Surgery* Vol. 53, Issue 8, pp. 1550–1554. Elsevier 2018. https://doi.org/10.1016/j.jpedsurg.2017.08.018

[7] Rintala, R. J. and Pakarinen, M. P. "Outcome of anorectal malformations and Hirschsprung's disease beyond childhood" in *Seminars in Pediatric Surgery* Vol. 19, Issue 2, pp. 160–167. Elsevier 2010. https://doi.org/10.1053/j.sempedsurg.2009.11.021

[8] Diseth, T. H. and Emblem, R. "Long-term psychosocial consequences of surgical congenital malformations" in *Seminars in Pediatric Surgery* Vol. 26, Issue 5, pp. 286–294. Elsevier 2017. https://doi.org/10.1053/j.sempedsurg.2017.09.009

[9] Berger, C., Casagranda, L., Sudour-Bonnange, H., Massoubre, C., Dalle, J. H., Teinturier, C., Martin-Beuzart, S., Guillot, P., Lanlo, V., Schneider, M., Molin, B., Molin, M., Mounier, O., Garcin, A., Fresneau, B., Clavel, J., and Demoor-Goldschmidt, C. "Personalized Massive Open Online Course for Childhood Cancer Survivors: Behind the Scenes" in *Applied Clinical Informatics* Vol. 12, Issue 2, pp. 237–244. Thieme Medical Publishers 2021. https://doi.org/10.1055/s-0041-1725185

[10] Wärnestål, P., Svedberg, P., Lindberg, S., Nygren, J. "Effects of Using Child Personas in the Development of a Digital Peer Support Service for Childhood Cancer Survivors" in *Journal of Medical Internet Research* Vol. 19, Issue 5, pp. e161. JMIR Publications 2017. https://doi.org/10.2196/jmir.7175

[11] vom Brocke, J., Hevner, A., and Maedche, A. *Introduction to Design Science Research* pp. 1–13. Springer International Publishing, Cham, Germany, 2020. https://doi.org/10.1007/978-3-030-46781-4_1

[12] Meuser, M. and Nagel, U. "The Expert Interview and Changes" in *Knowledge Production* Chapter 1, pp. 17–42. Palgrave Macmillan, Hampshire, UK, 2009.

[13] Braun, V. and Clarke, V. "Using thematic analysis in psychology" in *Qualitative Research in Psychology* Vol. 3, Issue 2, pp. 77–101. Taylor & Francis 2006. https://doi.org/10.1191/1478088706qp063oa

[14] Page M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Moher, D. "Updating guidance for reporting systematic reviews: development of the PRISMA 2020 statement" in *Journal of Clinical Epidemiology* Vol.134, Issue June 2021. pp. 103-112, 2021. https://doi.org/10.1016/j.jclinepi.2021.02.003

6 ACKNOWLEDGEMENT

I would like to thank my supervisors, professor Maria Letizia Jaccheri, professor Gunnar Hartvigsen, and associate professor Sofia Papavlasopoulou, for their support and guidance in this PhD project.