

Personalized preventive child health care

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Personalized Preventive Child Health Care
the “360°CHILD-profile” studies

Summary

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This present thesis describes the results of the longitudinal Mixed Methods research project with the aim to develop and evaluate a new tool for visualizing and theoretically ordering personalized health information of a child's health situation: the 360°CHILD-profile.

Chapter 1 elaborates on the background, goals and aims of the thesis.

The initiative for this novel approach for visualizing and theoretically structuring holistic health data in one image originated from the preventive Child Health Care-practice (CHC). Within the CHC-context, there was a need for gaining better access to and overview on relevant health data to support the simultaneous thinking processes required for preventive clinical reasoning. The experienced need led to the idea to theoretically structure health data in line with the ICF. Moreover, it was intended to reach an appropriate visual representation of a child's health situation that would facilitate the CHC to adopt the different concepts of personalized health care: prevention, prediction, personalization and active participation of care-users.

This PhD trajectory included the development and evaluation of a 360°CHILD-profile with the aim to deliver the CHC a suitable digital dashboard that provides direct access to and overview of the relevant health data. The ultimate goal was to facilitate preventive, personalized clinical reasoning and shared decision-making and to ignite a transformation towards a personalized CHC.

Part A focused on gaining insight in how to develop a reliable and valid tool for visualizing integral health information that is usable and meaningful within the CHC-context based on a theoretical concept.

Within Part B, the focus was on gaining insight in the question how to systematically introduce and evaluate this innovative visualization tool within real-life CHC-practice.

Chapter 2 presents the results of the pilot study on aspects of inter- and intra-rater reliability and concurrent validity of a preliminary version of the 360°CHILD-profile. Medical doctors, working within the Dutch CHC used the 360°CHILD-profile to estimate functioning and needed intervention of 4-year-old children. In total 26 personalized

360°CHILD-profiles were assessed. Each 360°CHILD-profile was assessed by two medical doctors at T1 and at T2 (4 months after T1).

Regarding inter- and intra-rater reliability, results showed Intra-class correlation coefficients of respectively 0.71 and 0.82 for overall functioning and Cohen's kappa's of 0.47 and 0.46 for needed intervention. Validity results showed a Spearman's correlation coefficient of 0.78 for overall functioning and a Cohen's kappa of 0.52 for needed intervention. After only a short training, acceptable results regarding reliability and validity were generated for the 360°CHILD-profile if used to assess child functioning. The 360°CHILD-profile's value on tracking change in functioning and decision-making on intervention needs further exploration.

Chapter 3 describes the stepwise development and validation process of the subsequent version of the 360°CHILD-profile. The delivered dashboard is an online accessible visualization of CHC-data that is based on the theoretical concept of the International Classification of Functioning, Disability and Health (ICF) and represents a child's health situation in accordance with international standards for representation of health data (ISO 9241-125).

This chapter offers an example of how to use a nested design model within the health care context to achieve visualization of a comprehensive overview of theoretically structured health data. The utilized model considers immediate upstream validation within four cascading design levels: Domain Problem and Data Characterization, Operation and Data Type Abstraction, Visual Encoding and Interaction Design, and Algorithm Design. The model also includes impact-oriented downstream validation, which can be initiated after delivering the prototype. During the developmental, a user-centered design was utilized to actively involve relevant stakeholders within a real-life context to deliver a 360° CHILD-profile that fits the CHC-context.

The delivered dashboard provides caregivers and parents/youth with online access to a comprehensible visualization of CHC data based on the ICF and offers a holistic view on children's health and "entry points" for preventive, individualized health plans.

Chapter 4 describes the study protocol of a pragmatic Mixed Methods feasibility research project, executed during the first and short introduction of the 360°CHILD-profile within real-life CHC-practice.

The research project comprised of two studies. The first study entailed an evaluation of CHILD-profile's usability and feasibility. The second study focused on evaluating the feasibility of executing a randomized controlled trial.

The project started with executing a feasibility RCT, which included measurement of the accessibility and transfer of health information in two parallel groups (1:1) of parents. Both groups received standard CHC-care and the experimental group additionally received personalized 360°CHILD-profiles. Quantitative measurements on the accessibility and transfer of health information were executed after an intervention period of 6 months. Then, when RCT's measurements were completed, quantitative measurement of 360°CHILD-profile's usability and feasibility were performed. After descriptive analysis of quantitative data, qualitative methods were used to reach deeper understanding of quantitative findings and to further explore the stakeholders' perspectives on the potential benefits of the 360°CHILD-profile. Quantitative data were used to purposively sample for semi-structured interviews and refine topic lists. Overarching themes for both types of data-sources were compared to generate integrative findings.

Chapter 5 presents and discusses the integrative quantitative and qualitative results of the part of the Mixed Methods feasibility study with focus on evaluating the usability and feasibility of the 360°CHILD-profile.

Usability was defined as "usable for presenting children's health situations" and "users expect it to be useful". Feasibility was defined as "potential attainability for implementation within CHC". In line with the framework for systematically introducing and evaluating an innovation in a preventive health care setting, presented by Fleuren, the level of use was assessed, as well as a broad variety of determinants that potentially influence the implementation process. These determinants related to the CHILD-profile itself, its potential users, and the organizational and socio-political context.

Participating professionals (n=17) discussed personalized CHILD-profiles with parents (n=27). Twelve interviews (parents and professionals) and two focus groups were performed. After integrating quantitative and qualitative data, the overall theme "readiness for implementation" emerged. Participants reacted enthusiastically about discussing the 360°CHILD-profile and appreciated the quick overview on holistic health information. The 360°CHILD-profile appeared to be useful and efficient for CHC-practice and users seemed

competent in handling and using the CHILd-profile within the CHC-context. However, implementation appeared to be hindered by substantial organizational issues, including the non-structured electronic medical dossier. This study generated valuable knowledge on how to get ready for implementation.

Chapter 6 presents and discusses the integrative quantitative and qualitative results of the feasibility RCT, which thoroughly investigated RCT-procedures and explored applicability of potential outcome measures for assessing accessibility and transfer of health information.

CHC-professionals (n=38) recruited parents (n=30) who visited the CHC for their child (age 0-16). Parents were randomized to “care as usual” (n=15) or “care as usual with, in addition, the availability of a personalized CHILd-profile during six months” (n=15). Quantitative data on RCT-feasibility were collected on recruitment, retention, response, compliance rates and outcome data on accessibility and transfer of health information (n=26). Subsequently, thirteen semi-structured interviews (5 parents, 8 CHC-professionals) and a member check focus group (6 CHC-professionals) were performed to further explore and gain deeper understanding of quantitative findings.

The used randomization strategy, measurements and interventions were feasible.

Recruitment of parents by CHC-professionals appeared to be problematic and influenced by organizational factors within the CHC-context like insufficient facilitation by CHC-management. The used outcome measures for assessing the accessibility and transfer of health information showed skewed outcome data, with relative high percentages of positive scores in both groups and a low applicability of relevant items on accessibility and transfer of health information.

The Mixed Methods feasibility study enabled to gain a broad insight in the complexity of executing an RCT within the CHC-context. This context seemed to require a more complex randomization strategy and trained research staff instead of CHC-professionals to recruit parents. Measures, potentially for evaluating 360°CHILd-profile’s effectiveness, must be further explored and thoroughly piloted before proceeding the evaluation process. Overall findings revealed that executing an RCT within the context of evaluating CHILd-profile’s effectiveness in the CHC-setting will be much more complex, time-consuming and costly

than already expected. Alternative designs including Mixed Methods research should be considered for the next phases of the downstream validation process.

Finally, **Chapter 7**, summarizes the development and evaluation process of the 360°CHILD-profile while reflecting on the methodological aspects of the longitudinal research project, especially the advantages of the choice for participative Mixed Methods design. Moreover, this chapter discusses the integrative main findings, which revealed some paradoxes.

On one hand, promising results were found on the usability and potential benefits of the 360°CHILD-profile for relevant stakeholders (parents, youth, CHC-professionals, other care-providers and policy-makers) and perceived self-efficacy by CHC-professionals and parents. On the other hand, the project revealed substantial (mostly organizational) barriers within the preventive CHC-context (insufficient prioritization and facilitation by management and a complex organizational structure) with regard to the implementation and evaluation process. Last but not least, chapter 7 further reflects on what the findings entail regarding future perspectives. Important questions addressed are how to get ready for implementation within the CHC-context and how to evaluate performance of the promising 360°CHILD-profile within this context. The quick overview on holistic health data that this tool provides is likely to be time saving and enables a comprehensible transfer of health information to parents. Moreover, it stimulates a more consistent and structured registry of relevant health data within the CHC. Most importantly, the 360°CHILD-profile specifically is designed to intuitively guide clinical reasoning in line with a more predictive, personalized and participative child health care.