University of Victoria | Graduate Studies

Notice of the Final Oral Examination
for the Degree of Doctor of Philosophy

of

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"Shared Decision Making Via Personal Health Record Technology As Normalized Practice For Youth With Type 1 Diabetes"

School of Health Information Science

Thursday, July 26th, 2018
10:00 a.m.
Clearihue Building
Room B017

Supervisory Committee:
Dr. Abdul Roudsari, School of Health Information Science, University of Victoria (Supervisor)
Dr. Karen Courtney, School of Health Information Science, UVic (Member)
Dr. Lee MacKay, Kootenay Lake Hospital Diabetes Clinic (Outside Member)

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Dr. Lynn Nagle, Faculty of Nursing, University of Toronto

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Dr. Nikolai Dechev, Department of Mechanical Engineering, UVic

Dr. David Capson, Dean, Faculty of Graduate Studies

Abstract

Engaging youth with Type 1 diabetes (T1D) in the self-management of daily tasks and decision making provides opportunities for positive health outcomes. However, emerging adulthood and care transitions are associated with decreased clinic attendance and diabetes complications. The process of shared decision making (SDM) comprises 4 key elements – acknowledge, consider, decide, act - and is identified as an optimal approach to making self-management decisions, yet it has been difficult to implement in practice. Personal health record (PHR) technology is a promising approach for overcoming such barriers. Still, today PHRs have yet to root themselves into care and present an opportunity for improvement in SDM and engagement in self-management decision making.

Using a sequential two-phased investigation, this dissertation describes how PHRs can be designed to enable SDM and integrated into clinical practice to engage youth with T1D in self-management decision making. Phase 1 proposed an integrated SDM–PHR (*e-PHR*) functional model justified by youth with T1D (*n*=7) and providers (*n*=15) via a user-centered design approach. Located within an interconnected EHR ecosystem, *e-PHR* integrates 23 PHR functionalities for the SDM process, whereby each SDM element was mapped to PHR functions with a moderate level of agreement between patients and providers (Cohen's kappa 0.60-0.74). The Phase 2 mixed methods, pre-implementation evaluation utilized an online measurement instrument and survey and individual interviews, underpinned by the Normalization Process Theory (NPT), to describe the four cognitive and behavioural processes (coherence, cognitive participation, collective action, reflexive monitoring) known to influence the success of complex socio-technical implementations. Youth with T1D (*n*=8), providers (*n*=11), and EHR/clinical leaders (*n*=8) in British Columbia participated. Reliability tests of NPT-based instrument negated the use of scores for the coherence and reflexive monitoring constructs. Qualitative results indicated that *e-PHR* made sense as explained by two themes for 'Coherence': game changing technology and sensibility of change. Participants strongly agreed (mean score=4.6/5) with 'Cognitive Participation' processes requiring an investment in commitment, explained by two themes: sharing ownership of the work and enabling involvement. Weak agreement (mean score=3.6/5) was observed with 'Collective Action' processes requiring an investment in effort, explained by one theme, uncovering the challenge of building collective action, and 3 sub-themes, assessing fit, adapting to change together, and investing in the change. Participants appraised *e-PHR* as explained by two themes for 'Reflexive Monitoring': reflecting on value, and monitoring and adapting. Finally, participants strongly agreed (mean score=4.5/5) that *e-PHR* would positively affect engagement in self-management decision making in two themes: care is efficient and care is person-centred.

The establishment of a *e-PHR* functional model is a precursor to system design requirements. Using the NPT framework, findings from the process evaluation indicated participants invest in sense-making, commitment and appraisal work of this technology. However, successful integration of *e-PHR* into clinical practice to positively affect engagement in self-management decision making will only be attained when systemic effort is invested to

enact it. Further research is needed to explore this gap to inform priorities and approaches for future implementation success.