MEDINFO 2019: Health and Wellbeing e-Networks for All
L. Ohno-Machado and B. Séroussi (Eds.)
© 2019 International Medical Informatics Association (IMIA) and IOS Press.
This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHTI190651

A Descriptive Review: Six Pediatric Personal Health Records

Cori Thompson^a

^a Global ICT Consulting, Victoria, British Columbia, Canada

Abstract

This descriptive review narratively synthesized themes and concepts from academic studies on pediatric personal health records (PHRs) from Medline EBSCO and CINAHL published January 1, 2007 to April 7, 2017. Reported features were summarized into a frequency table. Six studies in four countries reported PHRs for children with special health care needs, well-children, and adolescents. All studies advocated further development of such tools to improve healthcare. Such development might include children in the design phase.

Keywords:

Child, Personal health record, Review.

Introduction

This poster presents main findings from a descriptive review of academic literature on personal health records (PHRs) for children and adolescents (children) as a first step towards summarizing the evidence. PHRs have the potential to improve patient health outcomes by supporting patient interaction with and management of their own health care. PHRs may be defined as "a record controlled by the individual and may include health information from a variety of sources, including multiple health care providers and the patients themselves. The PHR is separate from, and does not replace the legal record of any health care provider... and may be stand alone or connected" (Office of the National Coordinator [ONC])[1].

Methods

A descriptive review methodology was chosen to identify any "trends or patterns" from published academic empirical studies, to "collect, codify and analyze numeric data" for frequency in pediatric PHRs, and to review a "representative sample" rather than being comprehensive [2]. For further rigour, the review relied on additional items from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (i.e., rationale, eligibility criteria, information sources, search, study selection, data collection process, data items, synthesis of results, study characteristics, limitations) [3]. The topics were the reported key information types and functionalities - or features - in pediatric PHRs. From the included studies, reported features were abstracted into a frequency table and the themes and concepts were narratively synthesized. The concept of pediatric PHR using terms "child" AND "personal" AND "health record" was searched in Medline EBSCO and in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) from January 1, 2007 to April 7, 2017. Excel tables were used to screen the returns, identify duplicates, and abstract and summarize findings from included studies. Inclusion

criteria were (1) on patient-controlled integrated or nonintegrated PHRs as defined by ONC, (2) designed for or tailored to children, (3) reported on key information types and functionalities, (4) primary studies or used secondary data, and (5) in English. Exclusion criteria included (1) PHRs designed and/or used for adults, (2) records not controlled by patients such as school health records, (3) pediatric medical records to avoid skewing the frequency counts, (4) commentaries, grey literature, and policy statements, and (5) although a formal qualitative assessment was not conducted to avoid excluding any of the few studies, an informal assessment excluded studies that reported too few features to avoid skewing frequency counts.

Results

Of 49 results, 3 duplicates were excluded, and 36 articles did not meet the eligibility criteria. Ten articles were reviewed in full. Subsequently, four were excluded: three reported too few key information types and one was not about a PHR. Table 1 compares key study characteristics of the six included studies from four countries. The studies were found to use 15 different terms for pediatric PHR. The frequency analysis listed fortyeight features: all six studies reported on reminders or notifications, privacy (confidentiality), and security; five reported on patient demographics, immunizations, problem list/diagnosis, medications, and secure messaging; and four reported on lab results, calendaring/appointments, and ability to grant limited access. Evidence from the six studies was synthesized into four main themes and concepts for pediatric PHR design and usage. First, the main value of a PHR was the potential for communication and care coordination with the care team. Many children have multiple care providers in different locations and specialities [4-7, 9]. Parents used the PHR as a tool to support care coordination. Second, intrinsic motivation to use the PHR is needed for empowerment. Empowerment includes a balance of taking and relinquishing control (e.g., a patient may choose not to view a test result prior to the visit, a patient may review the record for any missing information) [7]. Third, the adoption, usage, and usability of the records depended on the parents' coping ability with the child's condition [5-7]. The PHR could also be a vehicle for knowledge transfer about the child's condition between provider-parent and specialist-primary care provider, as well as a means for parent-parent support and identifying parents as experts in their child's condition [4-7, 9]. Pediatric PHRs also need to support parental responsibility for their child's health decisions, right to reliable, complete health information, parental control and accountability of the record, and the need for understandable information [6]. While there was mixed evidence for PHR adoption by parents [7], most studies provided evidence of PHR adoption. Further research is needed as PHR adoption might be

by "parents more engaged in their child's care" [9]. Last, privacy (confidentiality) and security were key especially for adolescents' PHRs where both legislation and meaninful use criteria needed to be met. Organizational policies may help ensure these criteria are met in the PHR design and use [8].

Table 1 - Characteristics of the six reviewed studies

First author	Study type	Record name	Population/
(Year)	Data source	(Stage)	Condition
Country		Integrated or	(Record
[citaton]		Stand alone	control)
De Graaf	Evaluative	huidhuis.nl	Congenital
(2014)	Primary data	PHR with	conditions
NL		treatment plan	(Patient
[4]		(Implemented)	owned,
		Integrated	provider
			accessible)
Popkin	Evaluative	eFOSTr	Organ
(2009)	Primary data	PHR	transplants
CA		(Prototype)	(Partially by
[5]		Stand alone	parents)
Rocha	Descriptive	PedMHR -	Special health
(2007)	Primary data	medical home	care needs
USA		record	(Partially by
[6]		(Design)	parents)
		Stand alone	
Schneider	Descriptive	Patient Knows	Serious
(2016)	Primary data	Best (PCEHR)	chronic
UK		(Implemented)	conditions
[7]		Stand alone	(Partially by
			parents)
Thompson	Evaluative	MyUFHealth	Adolescents
(2016)	Secondary	Portal	(Adolescent
USA	data	(Implemented)	controlled,
[8]		Integrated	proxy granted
			to parents)
Tom	Evaluative	Kaiser	Well-child
(2012)	Secondary	Permanente	(visits,
USA	data	child PHR	immunization
[9]		(Implemented))
		Integrated	(Parent proxy
			via own PHR)

While four studies described participatory design with parents, providers, and/or organizational representatives [5-8], none reported involving children or adolescents in the design phase. This maybe an area for future research [8]. Future recommendations also include providing training and real-time technical support within a supportive health care organization environment, and tailoring information to the parents' ability to cope with their child's condition [6-7]. There may be differences in PHR use for well-children compared to PHR use for children with complex health care needs [5-6, 9]. Further research is needed.

Conclusions

This review attempted to synthesize academic literature on pediatric PHRs. Limitations included: one researcher designed and conducted the review, the studies' findings might not be generalizable to other jurisdictions, it is possible the studies did not report all features, and, last, only one expression of the key concept and two databases were searched. https://www.crd.york.ac.uk/prospero/display_record.php?Rec ordID=75346 has been registered to address the limitations. All six studies advocated future research of pediatric PHRs.

References

- Office of the National Coordinator [ONC], Personal health records: What health care providers need to know. Accessed March 29, 2019: <u>https://www.healthit.gov/sites/default/files/about-phrs-for-providers-011311.pdf</u>
- [2] G. Paré, M.C. Trudel, M. Jaana, and S. Kitsiou, Synthesizing information systems knowledge: A typology of literature reviews *Information & Management* **52** (2) (2015), 183-199.
- [3] D. Moher, A. Liberati, J. Tetzlaff, D.G. Altman, and the PRISMA Group, Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement, *Ann Intern Med* **151** (4) (2009), 264-269.
- [4] M. de Graaf, J.E.E. Totté, H. van Os-Medendorp, W. van Renselaar, C.C. Breugem, and S.G.M.A. Pasmans, Treatment of infantile hemangioma in regional hospitals with eHealth support: Evaluation of feasibility and acceptance by parents and doctors, *JMIR Res Protoc* 3 (4) (2014), e 52.
- [5] J. Popkin, A. Kushniruk, E. Borycki, D. Guarin, L. Mozley, N. Kilarski, L. Robson, and W. Creed, The eFOSTr Project: Design, implementation and evaluation of a webbased personal health record to support health professionals and families of children undergoing transplants, *Stud Health Technol Inform* 143 (2009), 358-363.
- [6] R.A. Rocha, A.N. Romeo, and C. Norlin, Core features of a parent-controlled pediatric medical home record, ISO Press 129 (Pt 2) (2007), 997-1001.
- [7] H. Schneider, S. Hill, and A. Blandford, Patients Know Best: Qualitative study on how families use patient-controlled personal health records, *J. Med. Internet Res* 18 (2) (2016), e43.
- [8] L.A. Thompson, T. Martinko, P. Budd, R. Mercado, and A.M. Schentrup, Meaningful use of a confidential adolescent patient portal, *J Adolesc Health* 58 (2) (2016), 134-140.
- [9] J.O. Tom, C. Chen, and Y.Y. Zhou, Personal health record use and association with immunizations and well-child care visits recommendations, *J. Pediatr* 164 (1) (2014), 112-117.

Address for correspondence

cori.thompson@ictconsultingltd.com