

Empowerment, Digital Literacy and Shared Digital Health Records: The Value of ‘nothing about me without me’

H. ALMOND^{a, 1}, E. CUMMINGS^b, P. TURNER^c

a Department of Health Professions, Swinburne University of Technology

b School of Health Sciences, University of Tasmania

c School of Technology, College of Science and Engineering, University of Tasmania

Abstract. People with complex chronic conditions (CCCs), particularly those living in rural locations, experience numerous challenges in engaging with quality integrated healthcare services. The deployment of shared digital health records (SDHRs) has been promoted to lessen these issues. However, the implementation of them has actually exacerbated the problems and inhibited SDHR adoption and use with this cohort as well as amongst rural health professionals. Based on a larger study conducted with a rural community, supported to adopt and use their SDHR, this paper highlights one finding, an empowerment gap. This needs to be overcome if vulnerable healthcare users and health professionals are to be able adopt and use SDHRs and realise some of their promised benefits. Critically, the finding highlights the importance of these users being empowered as active participants in SDHR adoption and use including by overcoming the digital literacy challenges faced. The research demonstrates that traditionally marginalised people living with CCCs in rural communities can be empowered and benefit more from an SDHR in ways comparable with users from less vulnerable groups.

Keywords. Vulnerable People, Shared Digital Health Records, Empowerment, Digital Literacy.

Introduction

Internationally a major focus in contemporary healthcare research and delivery, is a recognition of the need to embrace and facilitate authentic participation of vulnerable healthcare users and their significant others. In the 21st century, healthcare provision is distinguished by its growing dependency on technology and its encouragement of a vision of an ‘ideal’ digitally literate healthcare user who has the desire to be empowered (engaged, included and valued) to make use of the technology support services offered [1]. According to the American Library Association, ‘digital literacy is the ability to use information and communication technologies to find, evaluate, create, and communicate information, requiring both cognitive and technical skills’ [2]. However, it is also recognised not all healthcare users are digitally literate or even health literate and numerous challenges remain before this optimistic vision may be realised [3].

¹ Corresponding author: Helen Almond, Department of Health Professions, Swinburne University of Technology. E-mail halmond@swin.edu.au

The availability of real-time information about healthcare decisions, made by healthcare providers, can allow for continuous feedback to help improve healthcare user outcomes. Likewise, real-time information provided by healthcare user can provide continuous feedback about their needs to the healthcare provider. This may support quality improvements in decisions about healthcare provision, such as the transitional mix of healthcare provider skills required during a person health journey [4].

For people living with complex chronic conditions CCCs facilitating empowerment involves acknowledging the personal and economic burden of CCCs including the increasing burden on healthcare service and expenditures [5, 6]. SDHRs potentially make it possible and affordable to design and implement applications intended for direct use by healthcare users and their providers. However, if benefits of digital healthcare are to be achieved for healthcare users and the broader healthcare system, more attention needs to be paid to embrace and facilitate empowerment [7]. Delivering this in practice is challenging especially as the current design and implementation of SDHRs and healthcare provider engagement has actually hindered adoption and use amongst many vulnerable healthcare user groups people living with CCCs [8]. Nonetheless, it can be argued that finding ways to empower these people, to address digital literacy challenges and to ensure active support of their health care providers is critical to the avoidance of a growing digital divide in healthcare.

Based on one finding from a larger study, conducted with a rural community, supported to adopt and use the SDHR, this paper's focus is on the realities of digital literacy and empowerment amongst a cohort of some of the most vulnerable healthcare users in Australia - people living with CCCs in rural locations. The research aims to highlight, in spite of challenges it is possible to empower these healthcare users, and their significant others, to play a direct role in decisions about their health and healthcare choices, including digital healthcare provision [9] through the adoption and use of a shared digital health record (SDHR).

1. Method

Based on a qualitative participatory paradigm, a community based participatory research [10] approach was developed and conducted across a Tasmanian community, rural area classifications 2/3 (outer regional/remote Australia) [11]. Ethical approval (H0013781) was acquired. Through purposeful sampling 19 research partners, aged 40-89 years, with two or more CCCs, were recruited from three rural settings. The partners were involved in the research from inception to conclusion.

Three phases of data collection were undertaken: pre-experience of a SDHR, registration and early engagement with a SDHR, and post-experience and engagement with a SDHR. Data collection techniques included group meetings, individual semi-structured interviews and the researcher's reflective journal. The data collection tools included audio recordings, group and individual semi-structured interview guides, and live interaction with a SDHR as a healthcare user. Data were collected over a 12-month period and incorporated concurrent data transcription and verification (member checking). Data analysis adopted a thematic 'Framework Approach' [12], which empowered the whole research community. The approach was structured in three phases: data description, data management and data interpretation. The phases were subdivided into five iterative stages: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation. By systematically linking the research objectives

to indexed labels, charted categories, mapped themes, key findings were identified. The approach to data analysis ensured the characteristics and experiences were thoroughly explored and consistently recorded.

2. Results and Interpretation

Based on one finding, the desire to be empowered (engaged, included and valued), from a larger qualitative study, results are presented in this section. To provide context, a summary of the research partners characteristics: the average age was 62.4 years, more than two-thirds of them were women, more than half described four or more CCCs, and almost three quarters had more than four current healthcare providers. All the partners had experience with computers in either or both a personal and a professional capacity. They stated, they were able to access internet via a 'landline': 15 partners used the internet daily at home; three accessed the internet outside their homes, at a community centre, family or friends; and one partner reported no personal use of computers.

People living with CCCs in rural communities need to feel empowered in their digital healthcare provision. This requires consideration of their literacy, language, culture and learning styles. In context, healthcare information imparted by SDHRs needs to be more inclusive than written paper-based information to reinforce healthcare-provider explanations of health problems and treatments. Empowerment by SDHRs needs to address and value the diversity of healthcare users to improve their understanding of CCCs, recognise their digital literacy, and their confidence and capability to be involved in decisions made. Ultimately to prompt the vulnerable person to implement health behaviour changes and improve their health outcomes.

[I'm] totally unaware of the computers ... I think they just scare me; I think it's just lack of practice. I can type on one I have used one. I did a book for Tafe ... I have got a mobile phone, I use it when I travel to the mainland so I ring or text and say ... (CH20).

The distinctive personalities, lifestyles and cultural attributes of vulnerable communities requires an inclusive approach to the adoption and use of their SDHR. That means, an approach that values individual distinctive literacy, language, culture and learning styles.

I try to participate, as much as I can, for the company I feel useless honestly, I stopped driving. I shall remain active with the [lifestyle program] I go to the access centre if I need a computer and help. I may not be as fast. I don't see it ... I need a decent screen and enlarged typeface (CH14).

Over time, experts in healthcare provision have developed their own language or 'jargon'. Although the use of 'jargon' in healthcare provision and more recently digital healthcare provision may simplify communication between members of expert technical groups and healthcare providers, because fewer words are needed to discuss concepts and practices, the use of 'jargon' in health system/care provider/user relationships is perceived as a 'secret' excluding language.

The headings are wrong. There is no logic. It's more difficult than it needs be. It's overcomplicated. Shared Health Summary - is jargon, it doesn't need a sub heading and the fact people have to ask how to use it, means it's not right (CH16).

The experience and opinion of current healthcare provision was one of being excluded and undervalued.

If my other Dr had what was it, access, then he could see my [CCCs] stuff and stuff like that. It wasn't a problem to me but it's a problem to [them]. I know it's my record but that was [them] and it was [their] point of view and [their] choice (O3).

An aim of quality healthcare provision is to be inclusive and communicate beyond the experts. Using plain language can help expand the knowledge of healthcare users who have unique experiences, education, and interests that they are more than willing and able to share. The less 'jargon' used in all healthcare system/provider/user relationships, the more inclusive healthcare provision becomes, ultimately reducing the physical and psychological burden of CCCs on all healthcare provision (compliance, duplicate visits, errors made because of misunderstandings).

When empowered to use their SDHR, vulnerable communities develop new ways of thinking about healthcare provision. They want to access supplementary healthcare information via their SDHR, explaining it as an opportunity to be included, organise, make sense of, and add value to the transitional health requirements. Having access to and integrating with an organised approach to digital healthcare provision achieves this.

If I go to a specialist in [town] he can tap in to it... it should be there at their fingertips. Professionals seeing me have to use it ... maybe all health professionals in the community will be linked and communicate that's a lovely ideal (CH21).

Literacy, health literacy and in the case of SDHRs, digital literacy needs to be considered. Providing access to or the sharing of any personal information requires clear, practical detail about what, how and why information is being shared. This involves the concepts of trust, relevance, empowerment, taking time to explain and explore any uncertainty in the understanding of which details are being shared with whom and why.

I haven't written the day I stopped smoking in there [SDHR] yet. I'll put it on because it's important, I've got to catch up with a lot of things, it only takes a little while to punch the numbers. I should of thought about adding the smoking thing I'll get that in for him [GP] (O2).

Ignoring these obligations can and will lead to misunderstandings and marginalisation, which will in turn lead to resistance to and failure of the introduction of any SDHR. For the research participants, empowerment in SDHR required, inclusion: engaging in collaborative relationships in an environment of mutual trust and honesty established through effective communication, and strengthening each other to feel capable and empowered; valuing and respecting the partners as healthcare and SDHR

users who learn, who can and will process relevant information, as well as react to changes in information; delivering the adoption and use of an SDHR in a personal and contextually relevant way; placing people living with CCCs in a rural community as central in decision-making about their healthcare provision.

You need as much info as possible; I think getting a story is getting as much information as possible. By asking a question you're getting the info on those lines only. It's a matter of getting communities involved. I think the community knowledge is very underestimated (O4).

If SDHRs are to be more effective than paper-based information in imparting healthcare information, and in reaching vulnerable communities to reinforce healthcare providers' explanations of health problems and treatments, interventions must be targeted in personal and contextually relevant ways to achieve improved knowledge and understanding of CCCs, confidence, and ability to be involved in decisions, clinical outcomes, and health behaviours.

From [a carer] perspective, she lost her voice. I had to represent her that [MyHR] would have been incredibly useful. To see and contribute to a health record I agree (CH23).

This can be achieved by healthcare providers and system developers adopting and implementing literacy, language, culture, and learning styles and values sympathetic to the vulnerable healthcare user. If these empowerment barriers can be overcome, there is reason to believe that vulnerable communities can be empowered and benefit more from SDHRs than those from less exposed groups.

3. Discussion

The research finding demonstrates the importance of empowerment; active listening to vulnerable healthcare user experiences, thus building capacity into future healthcare provision that is responsive to the diversity of personal and community experiences. Currently, healthcare provision continues to be delivered within a narrow, doctor-defined 'patient's agenda' at a designated time and venue organised to suit the healthcare provider [11]. Rather, it should be encouraged to accept and support the concept of the empowered healthcare user, their desire to be active partners, rather than considering them as 'threatening intruders trespassing into a forbidden zone' [1].

Acceptance, inclusion and access to technology and building digital literacy is critical to the empowerment of vulnerable communities. Encouraging the routine participation of healthcare users, thus empowering them and their significant others, as active partners in their digital healthcare provision, can significantly assist healthcare users and providers alike to understand and transition through their multiple diseases. Likewise, valuing the expertise of people living with CCCs in a rural community motivates them to challenge the need for interactive and cooperative relationships with their healthcare providers. Empowerment with SDHRs provides opportunity for healthcare users to become digitally literate, see new information and ensure that all their healthcare providers have access to their latest reports, and understand that experiences are key in the delivery of digital, person-centred quality healthcare.

The empowerment divide also relates to the fact that although vulnerable healthcare users have access to the right hardware, and can develop skills to use SDHRs, some people will not make use of the opportunities offered, because they do not feel empowered by their healthcare providers to do so, and do not think they will benefit. This condones the continued delivery of healthcare provision that marginalises and disempowers vulnerable healthcare users to obtain benefit from digital health tools.

Healthcare providers can only deliver the best care to all if they acknowledge the potential of SDHRs and other digital technologies. They need to become digitally literate in the use of these technologies in the workplace in order to empower healthcare users. Digital literacy is not just about technical skills, other considerations include, creativity, critical thinking and evaluation, cultural and social understanding, collaboration, the ability to find and select information, effective communication, eSafety and functional skills [13]. In summary, adopt a positive attitude towards technology and innovation and its potential to improve healthcare and outcomes.

4. Conclusion

Vulnerable communities need to be empowered during their transition through their CCCs. Empowering people living with CCCs in a rural community with their digital healthcare provision requires a considered approach to their complex transitional healthcare requirements, and a better understanding of their and their health care providers experience of their SDHR.

The slow adoption and use of SDHRs globally demonstrates the difficulties first in getting the concept right and then in unlocking the benefits, so that a SDHR is used to full effect. In addition, the care experience underlines the importance of ensuring the digital literacy of all end users is in place. All users need to be empowered with the digital health innovation. System developers and implementers need to explore how all people want to be empowered by their SDHR. A successful implementation will require both technical and adaptive change. The importance of assessing and addressing digital literacy, thus empowering the health care user and professional alike, in the roll-out of SDHRs should not be underestimated. The concept of empowerment, digital literacy and shared digital health records: the value of ‘nothing about me without me’ warrants further investment and research.

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