

Health Information Systems for Clients with Mild Intellectual and Developmental Disability: A Framework

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Abstract: Persons with intellectual and developmental disability (IDD) remain among the most vulnerable members of society and frequently face numerous barriers accessing healthcare services. Following our recent literature review identifying needs for persons with IDD, we propose that frameworks can be useful to identify the key components of person-centred health information. These will ultimately support the building of relevant Health Information Systems. This paper presents the initial development and content of the Person-Centred Health Information framework (PCHI) developed to support persons with mild IDD. PCHI is based on the Information-Motivation-Behavioral skills (IMB) model and its use in the design and development of Health Information Systems has the potential to improve health access and outcomes for persons with mild IDD.

1 INTRODUCTION

Due to the recent unprecedented advances in software and technology, Health Information Systems (HIS) worldwide are undergoing innovative transformations. HIS refers to the interaction between people, process and technology to support operations and management in delivering essential information to improve the quality of healthcare service (Almunawar and Anshari, 2012). HIS should not be a separate and independent component of the health system and should be designed according to the service delivery system with patients/clients in mind. HIS have the potential to deliver collaborative person-centred care delivery across the continuum of care.

The concept of person-centred care has been increasingly advocated in healthcare. Additionally, person-centred care is important for healthcare services, eliciting insights from patients/clients which foster improved working partnerships, thus providing healthcare services that better meet consumer needs (Delaney, 2018). However, person-centred care can give a subjective lived-experience perspective of IDD.

Persons with intellectual and developmental disability (IDD) represent one of the major disability groups in the developed world. IDD is defined and characterized by significant limitations both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behaviours which relate to everyday social and practical skills. Internationally, IDD currently affects around 1% of the population in high income countries and 2% in low and middle income countries (Maulik et al, 2011). For persons with mild IDD, difficulties in processing complex domain-specific statements, understanding healthcare information content and complying with treatment plans are common. Supporting persons involves supporting the person to fulfil basic needs, such as managing self-care and self-advocacy. Thus, the opportunity for persons to make choices are important to their quality of life. When developing HIS to support person-centred healthcare for use by persons with mild IDD, researchers and developers must account for their specific requirements.

New technologies are continuously being adopted in healthcare services. Additionally, developments in HIS have facilitated more effective

approaches to healthcare activities and increased ease of accessibility for vulnerable individuals (Bechtel and Ness, 2010). Modern HIS improves service quality in the healthcare service sector in general and in clinical treatment in particular, enhancing client safety (Rahimi, 2018). As a vulnerable grouping, further research is required regarding the use of technology to support persons with mild IDD, examining topics such as access to and effectiveness of healthcare services. This paper aims to address this by outlining a framework for person-centred health information for persons with mild IDD. The proposed framework extends the existing Information-Motivation-Behavioral (IMB) skills model to include engagement and communication, with a view to supporting and improving clients' self-care management and quality of life. Utilising this framework will inform and support the development and design of future HIS systems for persons with mild IDD. Through drawing attention to HIS design and accessibility, adherence to existing HIS standards for users with IDD can be promoted. Additionally, researchers can be encouraged to develop new interaction strategies to address the issues related to HIS design and usability for persons with IDD.

1.1 Research Question

As increasing attention is drawn to health disparities across the general population, data also demonstrates that clients with IDD experience even greater health inequalities (Kirschner et al., 2007). Beyond the realm of healthcare services, the general population routinely utilizes technology to obtain information and perform everyday tasks at a click of a button. However, most health care systems have been conspicuously slow to develop information system tools of comparable functionality for persons with mild IDD (Krist and Woolf, 2011). Therefore, this paper considers the central research question:

Which conceptual framework for person-centred health information can support the development of HIS for clients with mild IDD?

The question is addressed by:

- Reviewing academic literature to identify frameworks which have been used successfully in various support provision areas;
- Developing and presenting a framework which can be used to support HIS development for persons with mild IDD.

2 LITERATURE REVIEW

Our recent literature review (Alshammari, et al., 2018), identified six main barriers to the use and access of health information which are experienced by persons with mild IDD: (a) communication skill, (b) client engagement and satisfaction, (c) training/education for persons with IDD, (d) attitude and knowledge of healthcare professionals, (e) persons with IDD being excluded from health promotion and research, and (f) quality of accessing healthcare services. In this paper we are particularly interested in working towards the elimination of barriers to communication and engagement, and, in providing more details regarding the experience of persons with IDD when accessing health information. Furthermore, we describe relevant literature examining the accessibility of HIS for persons with mild IDD.

2.1 Barriers to Communication

It is estimated that 50% to 90% of persons with IDD experience a significant range of communicative challenges (Baker et al., 2010). It therefore follows that communication plays a key role in the formulation and adoption of any person-centred health information framework for persons with mild IDD. In our previous paper, we identified that persons with mild IDD struggle to understand information from their healthcare professionals or they themselves are not able to effectively communicate their thoughts or needs regarding their health condition (Alshammari et al., 2018). In addition, other studies (Chou, 2012, Mustika et al., 2014) identify that children with IDD can develop the ability to communicate and learn using such technology. Persons with mild IDD and their carers expect healthcare professionals to communicate well, both in terms of how they conduct information provision and their service relationships. Communication is an important dimension which can have a positive effect not only on a person's self-management of their healthcare, but also on additional factors including socio-demographic characteristics and a person's health literacy (Santana and Feeny, 2014). The increasing complexity of care pathways arising from the growing numbers of persons with mild IDD who experience chronic illness further increases the communication demands facing healthcare professionals. Unfortunately, such complexities also raise the likelihood of problems and errors, while resolving these problems rests more and more on sophisticated forms of communication

(Iedema and Manidis, 2013). Well-developed HIS can provide solutions to communication barriers, thus enhancing the patient-centredness aspect of healthcare systems.

2.2 Barriers of Engagement

Due to communication barriers, it is difficult for persons with mild IDD to engage with the health system. For example, during clinical consultations, the communication is often directly between the health professional and the carer - consequently, the person with mild IDD is left out of the conversation. To address this enhanced engagement for persons with mild IDD offers a promising pathway towards both better quality and more efficient care. This, in turn, should improve overall population health. Persons with mild IDD need the encouragement and support to be more confident and involved in their personal healthcare decision-making process, as those who are engaged as decision-makers in this way have been shown to be healthier and achieve better outcomes (Chinn, 2017). Thus, personal engagement in healthcare management has the potential to contribute to better health outcomes, and HIS have an important role to play in supporting this engagement. It is important that the barriers of engagement are properly considered during HIS development and solutions devised to address the key barriers for persons with mild IDD.

2.3 IDD and HIS

Existing literature exploring HIS often focuses on assistive technology and these studies touch on topics related to the using mobile technology such as increasing self-discovery and an increasing confidence in technology use (Chmiliar and Anton, 2015, Burke, 2017).

However, there are few studies on HIS for persons with IDD. The literature available on this topic mainly relates to hospital passports which some studies refer to as hand-held health records (HHHRs), logbooks, health passports or health diaries.

Northway et al. (2017) presented a review of hospital passport use in the UK for persons with IDD. In their review, they found that some health passports lack primary care information as well as a level of communication which supports expression and

understanding. However, this does not necessarily speak to the level of HIS technology because they were not considering a technological intervention. In addition, Nguyen et al. (2014) highlighted the use and benefit of hospital passports for persons with IDD, reporting that hospital passports could increase health-related knowledge and awareness of personal health issues for long-term healthcare activity. Conversely while their review is not explicitly for HIS technology content, they offer health passports as a solution for the improvement of hospital records and as a means to support persons with IDD in the long-term. Thereby, this would enhance knowledge and provide an awareness of personal health issues.

3 RESEARCH METHOD

Following a literature review (Alshammari et al., 2018) to identify and discuss the barriers to access health information, a review of existing models and frameworks used and acknowledged to improve health outcomes for persons with mild IDD was undertaken.

This iterative process involved a series of systematic steps (see Figure 1) and led to the development of person-centred health information framework. The process included a mapping of existing conceptual frameworks and models against person-centred health care requirements. Identifying similarities and matching elements of each existing framework was an important step and confirmed the strong relationship between health information and person-centred care. The Information-Motivation-Behavioral (IMB) skills model was identified as a starting point for building a conceptual framework for person-centred health information for persons with mild IDD. In actual fact, the IMB model emphasizes that people who are well-informed and motivated are likely to engage in activities that enhance knowledge and skills needed to perform focused behaviour, which allows them to obtain better health outcomes (Athilingam et al., 2017). In doing this, we developed the concepts of barriers to engagement and barriers to communication, and conceptualized them within the IMB skills model. The framework that we present here, the Person-Centred Health Information (PCHI) framework for persons with mild IDD, is its first iteration.

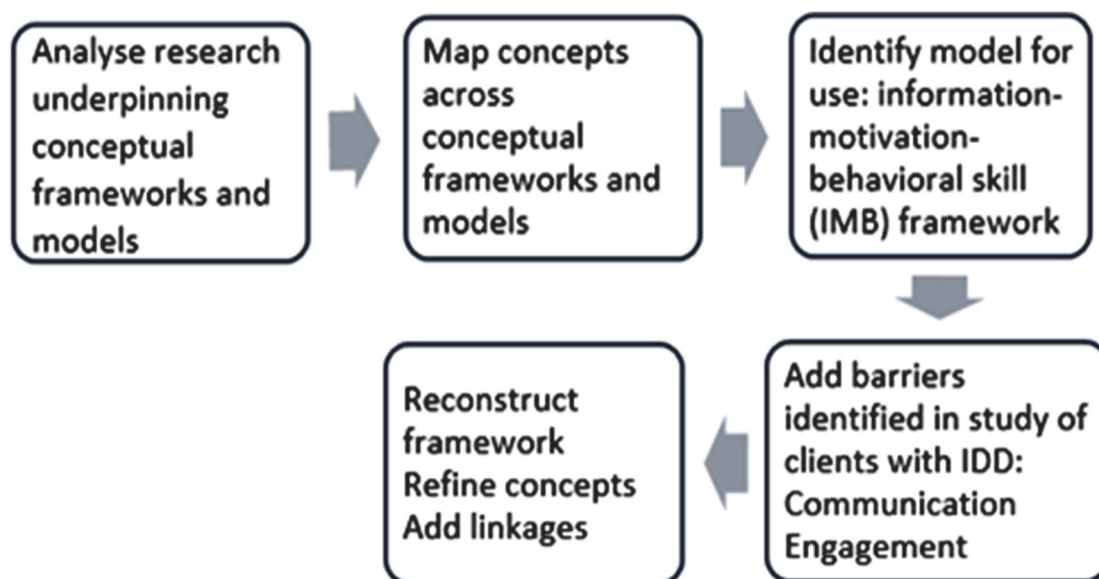


Figure 1: Processes used to develop Person-Centred Health Information framework (PCHI).

3.1 Information-Motivation-Behavioural Skills Model

The IMB framework demonstrates that, while information is a prerequisite for changing behaviour, information in and of itself is insufficient to achieve this change (Osborn et al., 2010). As a general social psychological conceptualization for understanding and promoting health-related behaviour, it purports that persons who are well-informed and motivated are likely to engage in activities which enhance the knowledge and skills needed to perform focused behaviour, and, in turn, are enabled to enjoy better health benefits (Fisher et al., 2003). The IMB model has three constructs: (1) information, (2) motivation, and (3) behavioural skills (Sabaté, 2003) and has been empirically validated across a number of diverse populations and health promotion behaviours.

While IMB is recognized as a credible model, a literature review conducted by Alshammari et al. (2018) identified a significant gap in knowledge for developing HIS. Thereby, considering the barrier to communication and engagement that must be considered when developing HIS for persons with mild IDD, we modified the IMB skills model to address these barriers. Within HIS, the accuracy of information is not sufficient as an output for persons with mild IDD to support the management of their personal healthcare. Communication and engagement are equally important and must be included in any framework supporting HIS development. Our proposed Person-Centred Health

Information Framework (PCHI) offers an extended version of the IMB model.

3.2 Person-Centred Health Information Framework (PCHI) Version 1

Figure 2 presents the PCHI framework for persons with mild IDD and variables not previously included in IMB are indicated by dotted lines. The inclusion of both engagement (Athilingam et al., 2017) and communication (de Jong et al., 2014) are essential as they have a direct bearing on health outcome. Moreover, the model proposes that communication and engagement factors may indirectly influence health outcome by means of behaviour change. In addition, the communication element may indirectly influence the health outcome via motivation. Engagement may also exert an indirect influence on health outcome through an understanding of health information and a stronger involvement with the healthcare professionals. This first iteration of PCHI has six components as described in the following sections.

3.2.1 Health Information

The simplest function of personal health records is to store information which may be entered by the person and can include hyperlinks to useful resources. Some personal health records personalise information for the individual and would incorporate motivational messages to help the person take action to confront

challenges, such as weight loss. When presenting health information to persons with mild IDD, we need to consider how they can process and use information. Therefore, the use of simple vocabulary or pictorial language which can be understood by persons with mild IDD could be implemented. This type of information is likely to be most effective both at the outset of care and in subsequent maintenance, and needs to include accurate information about available treatment(s) (Rivet, 2011). Additional information can also include health promotion advice and facts about preventive behaviour.

3.2.2 Motivation

In the past decade, there is a wide range of recreational software applications intended to promote various aspects of health-care, from simply helping people adhere to an activity schedule, get fitter, or to deal with the day-to-day care of chronic illnesses. Furthermore, the application of gamification is popular in physical health domains such as physical fitness, diet, and managing chronic illnesses (Werbach and Hunter, 2012). As motivation is at the heart of sustained behaviour change, games are deemed to be among the most powerful motivational tools (Deterding, 2015), and can be applied to many fields (Zichermann and Cunningham, 2011). The utilization of gamification in health-related contexts is growing. Many solutions are intended to promote wellness and consequently reduce the potential negative outcomes associated with unhealthier or risky behaviours (Institute of Medicine, 2001). For Deterding et al., (2011), “gamification is about making use of the underlying principles of gaming and applying them to any non-game activity”. Moreover, according to Zichermann and Cunningham (2011) gamification is “the process of game-thinking and game mechanics to engage users and solve problems, these definitions that unites concepts such: as serious games, advergaming, and games-for-change into a cohesive worldview that’s informed by the latest research into behavioral psychology and the success of social games.”

Games are broadly acknowledged as having the capability to expand persons' motivation. As indicated by the Federation of American Scientists, there are numerous elements which make a game motivating, a fuller understanding of which can aid the application of gamification in training (Sitra et al., 2017). Persons with IDD have demonstrated a strong

interest in video games (Mazurek et al., 2015) and those who are undertaking research into autism have also been increasingly interested in examining the effects of video game use. Consequently, many researchers have focused on developing applications of game technology for improving social and behavioural outcomes in persons with IDD (Durkin, 2010, Ern, 2014).

3.2.3 Engagement

Having persons with mild IDD become active participants in their healthcare is recognized as a crucial component of high-quality healthcare services, particularly in the treatment of chronic illnesses (Hale et al., 2011). Engagement, as shown in the PCHI, will encourage developers to consider the use of HIS in terms of their personal health record to enable data and information sharing between persons with mild IDD and their healthcare professionals. Thus, this also has the capacity to motivate persons with mild IDD. Motivation such as gamification can also be used to support engagement, as games are frameworks which are purpose-built for both enjoyment and engagement (Johnson et al., 2016).

3.2.4 Communication

This element of the framework focuses on effective communication between healthcare professionals and persons with mild IDD. Major goals within the category of communication from a HIS perspective are to facilitate easier access for persons with mild IDD to their health professionals, thereby reducing reliance on telephone or potentially unsecured email systems, encouraging persons with IDD to communicate using their own words, and empowering them to interact directly with their personal medical record. We propose that the communication construct within PCHI could enhance the communication channel between persons with IDD and healthcare professionals through meaningful involvement of all parties in the care process. The challenge for persons with IDD is in reframing healthcare professionals as partners who offer advice and identifying approaches which enable them to take responsibility for their health and wellbeing, such as engaging in self-managing behaviours (Santana and Feeny, 2014).

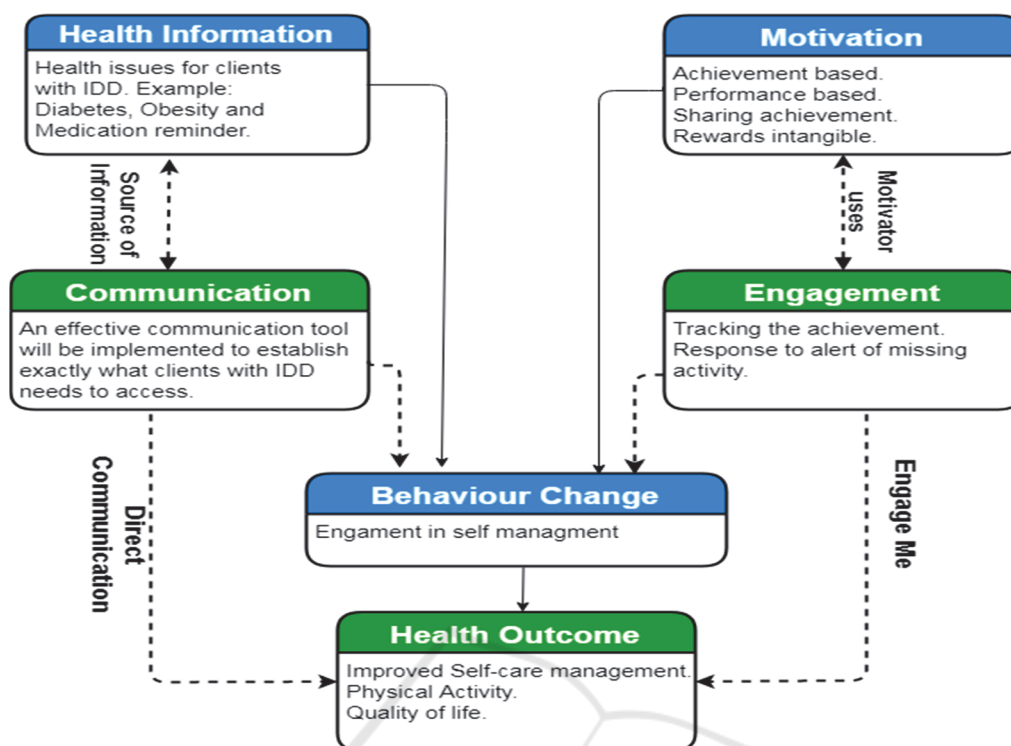


Figure 2: The Person-Centred Health Information Framework (PCHI) version 1.

3.2.5 Behaviour Change

As shown in the PCHI framework, both increased motivation and the provision of health information could encourage persons with IDD to change behaviour. This would support the implementation of a PCHI framework-based intervention because they are person-centered and goal-oriented. Several conceptual models of health behaviour change describe the factors influencing behavioural performance across disease contexts, with the ultimate goal of informing health promotion interventions (Elder et al., 1999).

Fundamentally, our framework asserts that persons with mild IDD who are well informed and motivated are likely to engage in activities that enhance knowledge and the skills needed to perform focused and relevant behaviour. Allowing persons with IDD to reap greater health benefits.

3.2.6 Health Outcome

At a general level, our framework emphasizes that undertaking positive health behaviour is a function of the extent to which individuals are well-informed, motivated, engaged and enabled to communicate. This will then enable the instigation of behavioural change, either personally or in conjunction with their

carer. To ensure that persons with mild IDD are not disenfranchised by the growing number of HIS, their requirements need to be considered in the development and design of such systems. PCHI provides a framework to support and inform such HIS developments. However, it must be recognised that persons with IDD may need further support from their carers and friends, which technology cannot provide, but may be able to influence.

4 DISCUSSION

In the general population, it is reported that people who directly communicate health concerns to their healthcare professionals have a greater degree of influence on the health outcome. In the interests of the individual and of equality and inclusion, this should also be the case for persons with mild IDD. It is an important behaviour in the healthcare context because information without accessibility cannot have any impact on their health unless it is consumed by persons with IDD. This paper has identified a set of framework components that should be considered during HIS developments. This framework can be used to guide HIS design with the intention of improving the health outcome for persons with IDD.

To this end, we have scoped the parameters of a design framework, PCHI, incorporating elements derived from the literature and a previously existing model, the IMB skills model. The value of this framework is that it enables us to proactively identify and understand person-centred HIS design for persons with mild IDD. Studies in the field of IDD highlight the benefits of person-centred health information from both the individual and organizational perspectives. The PCHI framework proposes that communication and engagement are additional intrinsic elements not previously included in such frameworks. As indicated through the IMB skills model, this need has not been identified for the general population. Our paper focuses on a specific population - persons with mild IDD, and has highlighted communication and engagement as a specific need for this population group. Indeed, it is possible that other specific populations such as those with dementia or older persons have similar requirements, but this is not within the scope of this paper. Design and development of HIS which consider and include the elements from PCHI can contribute to better health outcomes for persons with mild IDD. Our future work will involve the development of a prototype HIS through the involvement of persons with mild IDD. Furthermore, we will test it with a diverse population within a range of settings.

5 CONCLUSION

There is currently a crucial unmet need for PCHI targeted person-centered interventions that are easy to use by persons with IDD who experience cognitive difficulties and lack social support. The World Health Organization Report on Disability recommended the development of a person-centred framework for assessing people rendered vulnerable through issues of disability (World Health Organization, 2015). Such a framework can be useful for identifying specific health needs and challenges, assisting the decision-making for persons with mild IDD and their caregivers. This work commences that development. Considerable work remains to be done in terms of HIS development, implementation and evaluation. Healthcare professionals and family caregivers are critical partners in the plan for persons with mild IDD. As reliance on technology grows, we need to consider other elements which could be included in PCHI. There is more to be learned about the effect of person-centred health information on a person's health outcomes, and we may need to

consider, for example, safety and quality of care. Today, more than ever, HIS can play a pivotal role in enabling persons with mild IDD to become more independent and capable as they engage in their own healthcare process.

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