

1-1-2009

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Recommended Citation

Agostinho, Shirley; Sprod, Richard; and Harper, Barry: What spaces? Designing authentic, sustainable online learning spaces for children with diabetes 2009, 1009-1012.
<https://ro.uow.edu.au/edupapers/113>



What spaces? Designing authentic, sustainable online learning spaces for children with diabetes

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This paper presents a work-in-progress of how social networking, Web 2.0 and emerging communication technologies might be successfully used to support authentic self-management education for children aged 11-13 years who are living with Type 1 diabetes. The study employs a mixed-method approach that has been adopted within a Design Based Research framework. This paper explains the research problem, the theoretical framework that will underpin the study and the overall research design.

Keywords: learning communities, authentic learning, Design Based Research, diabetes education

Introduction

Type 1 diabetes is a disease that affects around 10,000 children and adolescents in Australia and requires constant insulin replacement and monitoring to reduce the incidence and progression of serious complications. (Maguire, 2005 p. 3) Many parents and young people struggle to cope with the demands of managing the condition, especially during puberty and adolescence. Competent self-management behaviours require high levels of knowledge, skills and problem solving abilities, for example coping with the practicalities of blood testing, calculating and adjusting insulin doses, estimating food intake and knowing how to deal with problems when they occur. In addition to these ongoing practical tasks there are important social and self-esteem issues that need consideration. For example, there are often conflicting priorities and perspectives of the young people concerned, their parents and clinicians as they deal with day-to-day issues. (Sawyer & Aroni, 2005 p. 406).

In Sawyer and Aroni's opinion it is the partnership relationships between child, parent and clinician that promotes best self-management behaviours and these relationships that have not been sufficiently studied. Balancing the 'sometimes competing perspectives of both young people and parents... is at the heart of what constitutes self-management for adolescents with chronic illness' (p. 406). This is supported by Schilling, Grey, & Knafl (2002) where they state that for young people, self-management is a life-long, active, and proactive process that involves shifting and shared responsibilities between the young person and the parent.

Social-cognitive and self-efficacy theory developed by Bandura (1997) is the basis of much of the current research in self-management education and support for people living with chronic disease. Dr Kate Lorig and colleagues at Stanford University are prominent in the development of successful patient-centred, peer-support programs that aim to help people maintain 'wellness in their foreground perspective' (Lorig & Holman, 2003 p. 1). Lorig and Holman state that 'self-efficacy must be considered a key program component, and the teaching processes must be structured to include the four ingredients of efficacy enhancement: performance mastery, modelling, interpretation of symptoms and social persuasion' (p. 4) Five core self-management skills are taught in these programs: 'problem solving, decision making, resource utilization, forming of a patient/health care provider partnership and taking action' (p. 2).

There is considerable enthusiasm in the literature for the redesign of health care processes to include the use of electronic communication technologies (e.g., Demiris et al., 2008; Jadad & Delamothe, 2004). In their white paper Demiris et al., (2008) argue that developers should involve patients' input in the design

of programs, patients should be active participants in decisions about their ongoing care, and programs need to be designed to be patient-centred and include both an educational focus and a peer social-support focus.

So what is the research evidence as to effectiveness of technology supported self-management programs? A meta-analysis of a broad range of technology facilitated interventions literature reported that when information (i.e., content information about the disease) is combined with peer support, these interventions did have a positive effect on knowledge, social support and clinical outcomes. It is more likely than not that those interactive interventions do have a positive effect on self-efficacy. Many questions resulted from this study including: how the interventions actually work, what are the essential features, what are the effects on health service utilisation, are there unintended or adverse effects, does this impinge on the patient-doctor relationship and interactions, training and support issues, and equity. These interventions might also have unintended harms such as being the source of false and misleading information, raise issues of privacy, quality and malpractice (Murray, Burns, Tai, Lai, & Nazareth, 2005 p. 21).

These findings are supported by Demiris et al. (2008) who state:

More research is needed, including rigorous, large-scale, longitudinal experimental studies and economic evaluations. Existing studies suffer from weak methodology including poor design (e.g., small sample sizes, inadequate follow-up), leading to inconclusive results. Scientific evidence of the effectiveness of patient-centred applications is required to further the field (p. 12).

Although there are many examples of information sites on the Internet about diabetes and self-management programs targeted at adults with diabetes and other chronic diseases, there is a paucity of reported research of educational interventions that employ online technologies to build peer-supported authentic learning communities for young people living with Type 1 diabetes. From the few studies identified (e.g., Newton, 2008; Wangberg, 2008) all have adopted an empirical approach, where attempts were made to measure the interventions' effect compared with normal care, rather than examining issues of design. Many papers reported problems with implementation including issues of design, technical issues, problems getting people to use the program, and longer-term sustainability. Research results typically lacked dose (e.g., length of time using intervention) and power (e.g., sampling strategy) and in many cases failed to demonstrate significant effect. Given these shortcomings it is time to re-think the approach to include the active participation of key stakeholders - in this case young people with diabetes, parents and clinicians, so that issues of design, effectiveness, implementation and sustainability can be addressed.

What space? What kind of technology-supported environment is needed?

Internet based social networking and communication technologies are becoming increasingly used by young people, creating multiple means for sharing and communicating. There is considerable interest in using social networking for the learning of skills and problem solving, 'call it community learning, communicative learning or collaborative learning, at its heart is a social process' (Owen, Grant, Sayers, & Facer, 2006, p. 11). Emerging affordances of these software and technologies have the potential to create dynamic and effective socially based learning communities for young people living with Type 1 diabetes if the design supports authentic contexts and activities, provide opportunities for collaboration, allows for articulation of beliefs, shared reflection, and has expert guidance. (Herrington, 1997; Herrington & Oliver, 2000; Reeves, Herrington, & Oliver, 2002) Developing self-management skills, knowledge and competency is a real-life, authentic, situated problem for the young people living with diabetes. It is not a formal educational problem per se, but an authentic life-skills problem. According to Sternberg (1993) real-life learning is founded in the notion of real-life problems that are often ill defined, require substantial information seeking, have multiple correct solutions and multiple ways of obtaining solutions. Solving these problems involves relevant prior experience, is often highly motivating, and involves emotional contingencies.

Methodology

The purpose of this research study is to examine how internet-based tools and communications technologies might be designed to support young people to learn diabetes self-management skills and to develop competency. The research focus is on the design frameworks required to support patient-centred, flexible learning communities where young people might be connected and actively engaged in shared problem solving and knowledge development at a time when they are developmentally ready.

The study aims to examine as broadly as possible how new technological approaches might be applied and is based on current learning and self-management theory. The research design is developmental and interpretive in nature and will examine a range of themes within a system that is designed to inform practical outcomes. Participants include young people (aged between 11-13), parents and clinicians that are actively involved, and data obtained during the developmental phases of the study will inform and guide the process. A Design Based Research (e.g., Barab & Squire, 2004; Baumgartner et al., 2003; Cobb, Confrey, diSessa, Lehrer, & Schauble, 2003; Collins, Joseph, & Bielaczyc, 2004; Reeves, 2006; van den Akker, Bannan, Kelly, Nieveen, & Plomp, 2007) framework has been chosen for this research as it offers the opportunity to explore a design problem in an iterative way with active participation of key stakeholders.

Phases of the design based research

Our research is planned in four phases and involves families and clinicians from the Women's and Children's Hospital, Adelaide South Australia, and experts in technology supported interactive learning design. Both qualitative and quantitative instruments are to be used in the phases of the research. These include surveys, interviews, online artefacts and self-rated competency instruments.

Phase One involves an exploration of the practical problems of learning about Type 1 diabetes with young people aged 11-13 years, a reference group of young adults who are successfully living with Type 1 diabetes, parents and clinicians. Relevant literature will contribute to the development of draft design principles that will be used to guide the actual design and development of the learning community.

In Phase Two, an Internet based intervention and associated tools, together with the enabling communications technologies, will be designed and developed. The focus of the research in this phase is on formative evaluation to inform the development process.

Phase Three focuses on the testing of the solutions - an authentic learning community and the associated technologies, with the young people, parents and clinicians. Two iterative cycles will be used, and formative evaluation will inform any modifications and additions that are required. The first cycle is limited to 6 young people and 4 weeks, the aim being to provide the researcher with an impression of how the learning community will work in practise. The second cycle, including any modifications, will be run with a larger group – up to 14 young people, and for a longer time – at least 12 weeks.

Phase Four will involve reflecting on the data collected in Phase Three. From this reflection, and emerging evidence from the literature, new design principles together with suggestions for further research will be developed.

Discussion and conclusion

The intersection of contemporary self-management theories, learning theories and emerging communication technologies are providing new and exciting opportunities to support young people living with Type 1 diabetes. It is clear that technology supported self-management interventions must not only be well founded in theory, they must also include the involvement of key stakeholders in the design, they must integrate into the everyday lives of the people impacted, be educationally and clinically effective and be sustainable into the future. This study attempts to find ways of achieving these aims.

Developing self-management competencies is a life-long process and adapting existing Web 2.0 tools such as social networking software in ways that are integrated, ubiquitous, and useful to all those concerned will enable connections between young people who are living with diabetes and enable them to rehearse ways of solving problems using technologies and ways of getting support into the future. The outcome of this pragmatic research will inform future studies where comparisons can be made, and modes of action examined.

This paper presented a work-in-progress on how Designed Based Research is being applied to examine the potentials of emerging communication technologies to support self-management education for young people living with Type 1 diabetes. Emerging evidence from this pilot research will be completed in 2010 and will lead to better-informed designs and empirical research in the future.

Acknowledgment

We wish to acknowledge and thank Professor Jan Herrington and Professor Thomas Reeves for their inspiration and guidance in this research.

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Please cite as: Sprod, R., Agostinho, S. & Harper, B. (2009). A dialogic approach to online facilitation. In *Same places, different spaces. Proceedings ascilite Auckland 2009*.
<http://www.ascilite.org.au/conferences/auckland09/procs/sprod.pdf>

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