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# **“The best place we can learn from is ourselves”: the Development, Implementation and Use of an Online Patient-based Community of Practice for People with Type 2 Diabetes**

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**Keywords:** learning design, activity theory, design-based research, patient-centred learning, type 2 diabetes, transformative learning

**Abstract:** This paper reports on the development, implementation and use of a patient-centred online community of practice for people with type 2 diabetes mellitus. In this qualitative study, the theoretical framework of activity theory is adopted to describe the complexity of the use of the system and to frame the evaluation of the use of the learning environment.

## **Introduction**

People who have been diagnosed with type 2 diabetes face particular emotional, psychological, medical and management-related issues as they go through a major transition in their lives (Lawton, Parry, Peel, & Douglas, 2005; Lawton, Peel, Parry, Araoz, & Douglas, 2005; Peel, Parry, Douglas, & Lawton, 2004). Although a vast array of studies have been conducted to examine how online technology can aid as a mode of the delivery of education for people with type 2 diabetes (Castelnuovo, Manzoni, Cuzziol, Cesa, Tuzzi et al., 2010; Dalton, 2008; Nuovo, Balsbaugh, Barton, Fong, Fox-Garcia et al., 2007; Wangberg, 2008) there are fewer studies that focus on social modes of online collaboration and learning (Greene, Choudhry, Kilabuk, & Shrank, 2011) for people with diabetes. This paper reports on a study that has developed and implemented an online community of practice for people with type 2 diabetes and is concerned with the question of whether participation in the community promotes transformative learning experiences.

## **Phase 1: Thematic development**

A range of individual interviews and focus groups were conducted in order to elicit themes from participants related to education and diabetes, living with diabetes, self-management strategies and relationships with health professionals.

**Methods.** Individual interviews (n=4) were conducted using a semi-structured interview schedule based on the McGill Illness Narrative Interview (Groleau, Young, & Kirmayer, 2006). Following on from the individual interviews, two focus groups (n=11) were held using a semi-structured interview schedule that was designed using the dimensions that emerged from the individual interview stage.

**Methodology.** Thematic analysis was conducted on the interview and focus group data using a contextualist approach (Braun & Clarke, 2006). Three broad themes featured in the analysis of the individual interview data – *the lived experience of diabetes*, *support* and *knowledge and understanding of diabetes*. The analysis of the focus group data produced a range of themes and sub-themes. These themes informed the initial design of the online learning environment. The most prevalent thematic patterns include the themes of *the lived illness*, *educational experiences* and *management experiences*.

## **Phase 2: Development of the learning environment**

**Thematic elements and tools.** The online system was constructed using the thematic elements that emerged during the analysis of the data. Lifestyle practices, for example, were rich and varied and this theme provided an opportunity to design activities that could give participants an opportunity to share ideas about various aspects of lifestyle behaviour such as nutritional practice or barriers regarding physical activity. The intention was for Twitter to be used as a tool for daily communication and for the forums in Moodle to provide the platform for deeper levels of communication.

**Methodology and theoretical assumptions.** The patient as an active and reflective participant in the construction of his or her management (Heinrich, de Nooijer, Schaper, Schoonus-Spit, Janssen et al., 2012) underpinned the design of the learning environment. This correlates with a pedagogical approach that was broadly constructivist approach in nature and the characteristics of all tasks were described using various vectors based on a 'learning design toolkit' (Conole, Dyke, Oliver, & Seale, 2004). The popular and easily configurable learning management system of Moodle was chosen as the tool to implement the learning designs.

The theory that was adopted to provide an analytical lens through which to view the various stages of the learning environment from its initial design to its subsequent use was activity theory (Engestrom, 1987). The theory states that all activity takes place in a complex environment of interrelated layers through which activity is constituted and mediated. Activity systems consist of six conceptual layers: subject, object (and outcomes), tools & mediating artefacts, rules, community and division of labour. None of these layers can be analysed in isolation from one another. For example, the intention was for participants in the website to engage in the object of the co-construction of a learning environment. This object cannot be conceived of without the participation of subjects of the activity. Tools and mediating artefacts can either be physical or cultural. The online learning environment was the main tool under analysis and this represents a set of aggregated physical tools whose affordances had the potential to contribute to collaborative discourse.

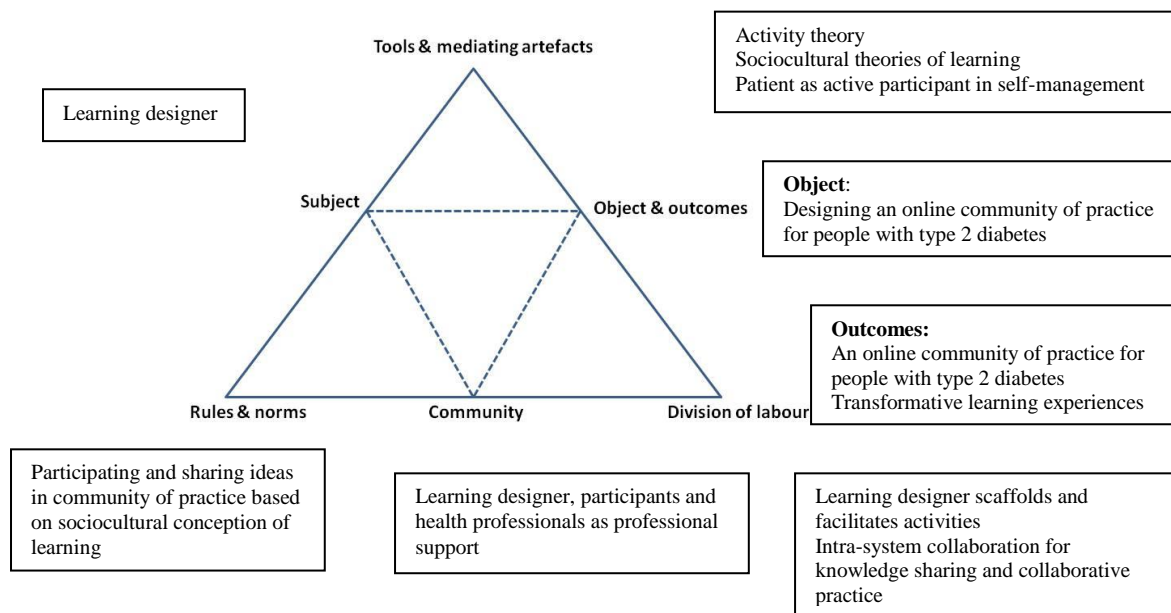
The relationship between the subject and community (such as allied health, doctors, specialists and the role of family support) is mediated by rules (explicit or implicit norms and conventions). The implicit rule that the health professional is at the centre of educational provision was challenged in the design of the learning environment since expertise in the practice of daily management is considered to reside with the patients. Similarly, the responsibility for the creation and interpretation of educational content is traditionally weighted more heavily towards the health professional. The division of labour implied by the design of the learning environment challenged this assumption. The model of the design of the learning environment is captured in figure 1.

## **Phase 3: Use of the learning environment**

Four groups (n=12) used the website (diabetesed.com.au) over a period of 12 months from March 2014 to March 2015. This paper focuses on the analysis of the first group to use the website from March to May 2014.

**Methods.** Participants to the study were required to have type 2 diabetes and be over 18 years of age. The first group, consisting of two males and two females, was formed in March 2014.

Sim-card based iPads were chosen as the technology of choice because the study is geographically located in an area of significant social and economic disadvantage and the iPad provided the opportunity for the project to be of interest to the largest number of people in the community. A common device also meant a potential reduction in the technical support burden since all participants would be using the online learning environment on one device. Recruits were provided with basic instructions in the use of the system, how to use Twitter and they were provided with a resource which they could refer to for basic tips on how to use the various features of the system. Participants were then required to use the online learning environment as individual users before being placed in a group. This is called the individual-use phase and group-based participation is called the group phase. Four semi-structured interviews were conducted before the individual-use phase and two semi-structured interviews were held after the individual-use phase and before the group phase. After an eight week period of participating and engaging with the online learning environment, a final group-based semi-structured interview was conducted. Two members of the group participated in this interview.

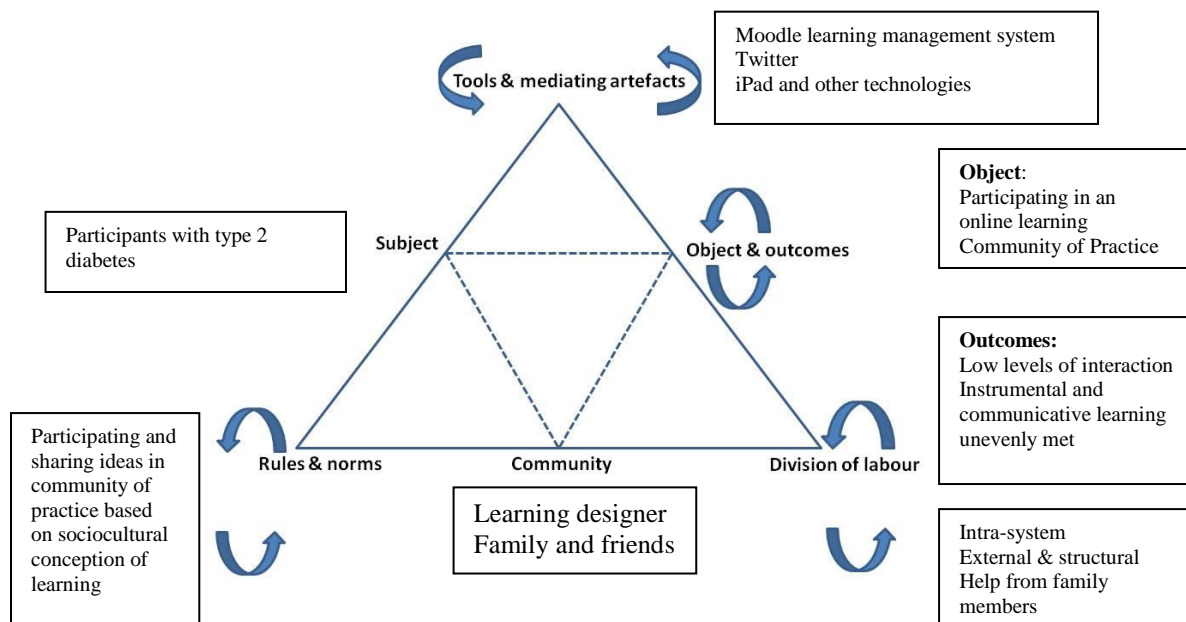


**Figure 1.** Design of the environment

**Methodology and evaluation.** The analysis of the interview data informed by activity theory revealed several tensions between dimensions represented in the model. These are graphically illustrated by the arrows in figure 2. Disembodied online experiences dampened the enthusiasm to participate and significantly contributed to the way in which the division of labour in the group was distributed. This had an impact on the intended outcomes envisaged in the design of the environment. Tensions at the level of the various dimensions of the model in figure 2 provide us with a plausible explanatory path.

Participants were unfamiliar with the educational and interactive norms associated with the learning tasks. There were varying degrees of competence with the adopted

technologies which caused some confusion and the use of Twitter as a tool for communication was not taken up. Additionally, the tasks were not perceived as separate weekly tasks and this increased the level of navigational complexity. In terms of the division of labour there was too great a gap between the level of participation exhibited by the group members and the level of engagement required to meet the intended outcomes. Interestingly, however, an outcome related to the individual use of the learning environment did lead to increased awareness of the sub-optimal nature of her nutritional practices. The dimensions associated with instrumental knowledge (improving nutritional practices, for example) did not figure in any discussions and neither did any interaction that might be defined as characteristic of communicative learning and rational discourse (Mezirow, 1994). Even though all of the members shared what Mezirow would call a ‘disorienting dilemma’ (Kitchenham, 2008) in the form of type 2 diabetes this was not sufficient to establish a community of practice (Wenger, 1998) of shared experiences, ideas and management strategies through which participants might share instrumental and communicative dimensions of learning.



**Figure 2. Use of the environment**

The fact that a shared diagnosis did not contribute to high levels of ‘social presence’ and instant rapport with other participants in the network suggests that sharing common health experiences may be a necessary but not sufficient condition for interactive engagement in a shared interest online learning community. The problem that confronts health-based learning environments is that they are, to a certain extent, a reflection of the concept of the sick role. The sick role, however, only allows for the performance of the sick role at the expense of other rules that one may legitimately perform (Varul, 2010). To concentrate on the establishment of a ‘shared domain of interest’ that is based solely around the shared experiences and practices associated with being chronically ill may therefore be problematic. A domain that is too narrowly defined may also have an impact on the conditions that Mezirow (Mezirow, 1994) indicates are necessary for participating in rational discourse.

## **Towards a conclusion**

This paper reports on the development and evaluation of an online community of practice for people with type 2 diabetes. It is a qualitative study concerned with exploring the question of whether participation in an online community of practice for people with type 2 diabetes promotes transformative learning experiences. In order to investigate this question activity theory was used to articulate the initial design of the system and to frame the evaluation of the use of the system by one group.

Participants were fairly comfortable with the technology that they were required to use although there was a degree of confusion with the range of collaborative options that were available to them. The technical dimensions of the tools, in other words, did not function as significant barriers to engagement with others. What did present itself as a recurring theme was the experience of being a “one man band” and not feeling part of a learning community. The absence of social presence (Kehrwald, 2007; Rourke, Anderson, Garrison, & Archer, 2001), which is one of the elements of the Community of Inquiry Model (Rourke et al., 2001), was significantly felt and this contributed to what we have called the disembodied online experience. A narrow definition of a ‘shared domain of interest’ might also have contributed to the lack of interaction. In subsequent iterations of this design-based research study (Anderson & Shattuck, 2012; Design-Based Research Collective, 2003) participants were required to meet face-to-face and this reflected a change in the initial design.

Initial analysis suggests that this modification might not have resolved the tensions that have led to low levels of interaction. If division of labour is viewed both as a lens to explore intra-system interactions and as a way of understanding how time is consumed by quotidian and other tasks during people’s lives this dual reading can contribute to a broader understanding of structural barriers to engagement and participation in learning activities in the present context. Ongoing analysis of the data will continue to explore this and other lines of enquiry.

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