Supporting Patient Decisional Needs Through Online Health Communities

Jing Zhang
University of California San Diego, San Diego, CA, USA
jingzhangabels@gmail.com

Abstract. As of 2014, 29.1 million people in the US and 422 million in the world have diabetes. Diabetes has a substantial and increasing impact on the quality of life. Patients face the burden of self-management and have day-to-day decisional needs when they attempt to find out about their choices and decided on the next course of action. The field has under-explored these decisional needs. To this end, I aim to investigate how patients make decisions in online health communities and present solutions to provide balanced and comprehensive information to better support patient decisional needs.

Introduction

Diabetes is a chronic condition characterized by elevated levels of blood sugar which over time leads to serious damage of the heart, blood vessels, eyes, kidneys, and nerves (Diabetes Programme, 2017). It has a substantial and increasing impact on quality of life. Online health communities (OHC) offer patients with chronic illnesses the opportunity to share information and to learn from others with similar experiences. Thus, OHC present a opportunity for us to improve the quality and usefulness of information provided and to create interaction that can improve informed decision making (Kummervold et al. 2002). To do this, I will uncover patient decisional needs in online health communities, and then test solutions to support such decisional needs.

Background and Significance

People with diabetes make decisions everyday of their lives that will affect their health (Association of the british pharmaceutical industry 2006), and express high desires for information (Duggan & Bates 2008). However, there is a lack of information provided to patients after their formal diagnosis (Beeney et al. 1996; Peel et al. 2004; Duggan & Bates 2008; Lamberts et al. 2010). As chronic illness changes over time, patients transition out of stable phases (Corbin & Strauss 1991) and experience increased self-awareness and the seeking of empowerment, through the process of learning, making choices, and identifying changes needed (Emery...
2003). As a result, they inquire and evaluate their choices to decide on the next course of action, and need to keep themselves up-to-date about new medications and approaches to care (Association of the british pharmaceutical industry 2006). Consequently it is especially important to provide informational support to aid informed decision making, a process that involves various resources and understanding pros and cons of diverse information. To this end, I first aim to study how patients express decision making through OHCs to understand their decisional needs. Second, I will integrate clinical evidence into peer conversation and examine its effectiveness.

Research Approach and Results

Aim 1: Uncover patient decisional needs in OHCs

Method
To uncover patient decisional needs, I conducted a qualitative content analysis of OHC posts. The dataset included 8690 thread initiating posts from an online diabetes community between 2007 and 2014. I then randomly sampled 1000 posts (~11.5%) for analysis. To guide the content analysis, a codebook was developed to provide instruction on extracting posts relevant to decision making.

Results
The findings show that decision making takes place in approximately 20% of OHC member initiated posts. In-depth content analysis revealed the context surrounding decision-making: what topics patients attempt to make decisions on (Figure 1), and what triggers them to make such decisions (Figure 2). These contextual findings can guide us in devising materials covering the topics patients care most about when they make decisions. Additionally, knowing what triggers patient to make decisions help situate decisional support in context of their illness trajectory as well the broader social context.

Figure 1. The topics of decision making
Figure 2. The triggers of decision making
Aim 2: Develop and test solutions to support decisional needs in OHCs

In this aim, I will test the solution of integrating clinical evidence to peer patient conversation in OHC. Specially, I address the following two research questions: 1) will additional clinical evidence would be perceived useful by patients? 2) will additional clinical information improve informed decision making (measured by self-efficacy and self-care)? To answer these research questions, I worked with a clinical collaborator to generate clinical content to add the peer patient conversation, and started a randomized controlled trial involving diabetes patients.

Method

12 OHC posts containing decision making from Aim 1 were selected to represent a diverse range of topics concerning patients at various stages of diabetes. The clinical collaborator was given the 12 posts, including the inquiries and patient responses. She was tasked to provide comment as necessary to help answer the question in the inquiry.

The patient participants are divided into test and control group, where the control group is given the 12 posts with only peer patient responses, and the test group is given the 12 posts with clinical evidence integrated. The clinical collaborator who provided the clinical content is identified as ‘UCSD_NursePractitioner’ in the post. Questions to assess how useful patients perceive the conversation thread in the post are added at the end of each post. These 12 posts with assessment questions are called ‘small surveys’ and are administered to them 3 times a week for 4 weeks.

Additionally, a pre-survey, a post-survey, and a follow-up survey to measure patient self-efficacy and self-care activities are administered immediately before, immediately after, and 2 weeks following the conclusion of the study. Optional exit interviews were conducted as part of the study as well. Thus far 66 participants are eligible and 46 have enrolled in the study. A stratified randomization approach was used to balancing diabetes diagnosis, internet usage, and gender, when assigning patients to control or test groups.

Preliminary results

The small surveys contain 10 questions that assess the perceived usefulness of information. Participants rate on a scale of 1-7. The higher numeric value indicates more usefulness or higher satisfaction perceived by the participant. T-test shows that participants in the test group (with clinical evidence) find the information more useful than the control group (without clinical evidence) (p<0.05). The findings also show that in order for the information to be useful for patients, the content should be relevant, specific, and new. While personal
experience is valued, health professional’s’ opinion or verified information is desired. And in order for the health professionals’ input to be useful, it has to add value and meet patient’s’ expectation.

References

Association of the british pharmaceutical industry, 2006. The Diabetes Information Jigsaw Seek knowledge for informed choice and better health.


