

Diabetes Education In Everyday Living Through Participation In an SNS

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Abstract

This ethnographic research explores how adult users of a social networking site focused on diabetes educate themselves about living with this condition. This paper brings attention to the emerging phenomenon of people with chronic conditions congregating on SNSs for health that has not been acknowledged by the research on SNSs before. It also sheds light on the ongoing education in settings other than the clinics. It shows how these settings support, draw from or subvert the traditional forms of diabetes education.

Keywords

SNS for health; education in everyday living; diabetes education

This paper is based on ethnographic research that explores how adult users of a social networking site (SNS) focused on diabetes educate themselves about living with this condition. The purpose of this research is twofold. Firstly, to explore and describe a slice of the everyday educative processes in the face of a life change event like diagnosis of diabetes. Secondly, to explore how SNSs serve as the sites and mediators for these educative processes. I collected data in two stages, firstly by hanging out on the SNS as a participant observer for 17 months. This meant visiting the site regularly, participating in the activities going on, and actively keeping a journal about my experiences. Secondly, by downloading archival data from publicly available sections from March 2008 when the site was first launched in beta.

In this paper I highlight one part of this research that looks at the temporal aspect of the educative process that is activated when a person is told they have diabetes. Analysis of activity of one person over time shows how the deliberations were transformative over time from one situation to another and one conversation to another.

Background

The American Diabetes Association (2007) estimates 1.6 million new cases of diabetes are diagnosed in people aged 20 years and older each year. A chronic condition like diabetes affects every aspect of the body as well as all aspects of life. Unlike, acute diseases, the patient role for a chronic disease is stretched out throughout the patient's life in addition and parallel to other family and social roles they play. In spite of the push for diabetes self-management education as a solution to 'compliance', two thirds of people diagnosed with diabetes are still labeled 'non-compliant' – failed diabetics. This has prompted further research that focuses on 'Why don't patients do what they should and how can we get them to do it?' Labeling a patient compliant or non-compliant diabetic ignores the everyday efforts of patients to cope with their changed circumstances and translate the diabetic regime into everyday living.

The construction of self-management education as 'empowering' in the medical discourse misrepresents power as something to be given by doctors to patients. Power, in reality, is embedded in ongoing interactions. Similarly, educated diabetic is not a state achieved at the end of a workshop by filling the known gaps of specific knowledge deemed important by the 'experts'. It involves an ongoing process of translating the diabetic regime into everyday living. Thus there is a need to focus

on the question ‘what patients are doing everyday to live with this condition and how are they doing it?’

With the proliferation of the Internet and communication technologies (ICTs), medical professionals and policy makers are increasingly thinking of Internet as a vehicle to impart ‘legitimate’ knowledge about health and management of chronic conditions like diabetes. At the same time patients and caregivers are using social software like blogs, forums, podcasts and SNSs to engage in conversations they find educative (Fox & Purcell, 2010). I based my explorations of the SNS on the postulate that ‘people everywhere, unceasingly, and always in concert with others, work at changing themselves and their consociates through often difficult deliberations’ (Varenne, 2007). This educative process of figuring out that they do not know, what is there to be known, instructing ignorant others is the focus of the study.

Data Collection and Analysis

To look at the journey of a newly diagnosed person more closely, I collated all the activity of a newly diagnosed participant named Y1s in the discussion section for three months after she joined the site. Out of the 222 discussion threads, twelve were discussions she started and remaining were replies to discussions posted by others.

I coded text in each post in two ways - 1. by actions for example - asking info, asking opinion, giving info, sharing experience, expressing concern, agreeing, noticing and so on and 2. by content thematically. I used the coding as index to get to the instances of these themes rather than counting how many times a particular theme appeared. I also looked at how Y1s positioned herself over time.

Findings

The conversations showed how Y1s discovered the web of diabetes she got caught into with institutions, people, her body, and tools that constantly define and teach what it means to be a diabetic.

I looked at Y1s’ journey after diagnosis in terms of the process Lave and Wenger (1999) refer to as legitimate peripheral participation. The process of moving from newcomer to somewhat new, to old timer in the SNS and as a diabetic for Y1s was made up of getting instructed – experiencing – then instructing based on previous instruction and her own experience. Y1s learned from other’s instruction based in sharing stories of their experience in a situation. She then put it in practice and shared her story back to instruct another newly diagnosed who came after her. Lave’s theory of learning as participation helps see this process as movement along the plane of participation with multitude of positions in relation to others that Y1s can take instead of just two points of novice or expert. However, I found that this process is not linear. participation in DC is a cycle of learning and teaching. As participants go through life they find themselves on the periphery of ever newer fields of participation as people with diabetes and participants on DC.

There was a lot more that Y1 and participants she interacted with had to ‘figure out’ in order to apply the abstract/generalized knowledge that they receive from health professionals in structured interactions. The diabetic regimen is not just behavioral prescriptions that can be followed in a vacuum but these prescriptive practices had to be implemented in conjunction with other social practices involving other individuals, institutions, and spaces. Moreover, a standardized curriculum and guidelines abstracted from various experiences of bodies had to be relearned by for their own particular body. Not just knowledge of ‘a body’ but understanding of one’s own body is necessary.

The step of finding the SNS and asking questions was a deliberate step by participants to seek people who will instruct other than or in addition to the health professionals who are authorized to do so. However, it was not an either/or. At various times Y1s sought instruction from various resources and

selected who or which instruction to follow based on her circumstances, long term and short term goals.

Conclusion

As Walkley (2009) pointed out, health education is ‘social, ubiquitous, and partially authorized by authorities’ and there is little research on these ‘unscripted, unobserved educational moments’. This enquiry is an effort to make some of these practices in SNSs visible. It showed that patients and caregivers have much that needs to be learned on the way and instruction from health professionals is not enough and also not the only instruction that people actively seek. Following Y1s journey shows this work being done every day. Making this process visible hopefully will prompt health professionals to rethink the propositional and procedural knowledge they deem important as just one aspect of learning to live with diabetes and re-present the discourse about ignorance and compliance.

References

- American Diabetes Association (2007). *National Diabetes Fact Sheet: general information and national estimates on diabetes in the United States, 2007*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2008.
- Fox, S., & Purcell, K. (2010). *Chronic Disease and the Internet*: Pew Research Center.
- Garfinkel, H. (1967). *Studies in Ethnomethodology*. Englewood Cliffs.
- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge university press.
- Varenne, H. (2007). Difficult Collective Deliberations: Anthropological Notes Toward a Theory of Education, *Teachers College Record* 109:7, 2007, p. 1559-1588
- Walkley S. (2009) Comprehensive Health Education and the Quest to Change Behavior in *Theoretical Perspectives on Comprehensive Education: The Way Forward*. Lewiston, NY: The Edwin Mellen Press, 2009

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