Datafied Modelling of Self–Disclosure in Online Health Communication

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INTRODUCTION

People are seeking and sharing health information online in greater numbers as information and communication technologies (ICTs) advance (Oh, & Syn, 2015). Seventy-two per cent of adult internet users in the United States have reported looking for medical information online (Rideout, & Fox, 2018). Online health support communities (OHSCs) have risen to prominence as a valuable resource for doctors, patients, and caregivers (Liu, Liu, & Guo, 2020). The literature shows that online health support communities play a critical role in creating a virtual space that is accessible to people from all over the world for those dealing with potentially fatal diseases (Abiola, Udofia, & Zakari, 2013; Huang, ChengalurSmith, & Pinsonneault, 2019). This is especially important for chronic diseases like diabetes, where patients expect not only to receive ongoing medical treatment but also to receive support and companionship from others who have had similar experiences. In exchange for personalised suggestions and peer support, one user participation mechanism commonly seen in online health support communities is the generation of a large amount of personal information and emotional feelings (Fernandes, & Costa, 2021). According to previous research, online health support community users are willing to share their personal information publicly to take advantage of the convenience of online services (Atanasova, Kamin, & Petrič, 2018; Cavusoglu Phan, Cavusoglu, & Airoldi, 2016; Jozani, Ayaburi, Ko, & Choo, 2020). Online health support community users can gain medical knowledge, emotional comfort, and strengthen both online and offline social connections through active engagement (Wang, Zhao, & Street, 2017). As a result, user-generated content, particularly those involving self-disclosure, are the fundamental building blocks that distinguish online health support communities and contribute to both the provision and the seeking of social support.

Although online health support community users' information disclosure "may meet their basic needs for obtaining social support and forming social connections, when they give up some degree of privacy and personal control," they risk exposing their personal data (Liu, Miltgen, & Xia, 2022). Meanwhile, disclosed personal information leads to easily retrievable digital traces that can be collected by a variety of parties, resulting in unexpected privacy intrusions (Jain, Sahoo, & Kaubiyal, 2021) such as malicious attacks (e.g., phishing), illegal interests (e.g., doxing), and crimes (e.g., burglary, racketeering, and robbery). According to Walters (2017), most adult internet users are concerned about their personal information being disclosed on the internet, which can be used to identify a user's political inclination, purchasing habits, lifestyles, and so on (Wu, 2019).

As a result, digital footprints can be consolidated to profile a person efficiently and precisely, revealing more information than ever before. Health data, as a type of personal information, is extremely sensitive and valuable, if not the most valuable, to not only the individuals who possess it but also to companies and governments, particularly when the contents are expressed through personal narratives (Ma, Zuo, M., & Liu, 2021). Users' lack of awareness of privacy management during information exchange in online health support communities may result in the disclosure of personal characteristics such as identity, medical records, test results, and insurance details, to name a few. Furthermore, sensitive information like this can accumulate over time, resulting in unintended consequences and biases against users, even if the disclosure is intended for seeking or providing support with fellow online health support community users. For example, a patient's therapeutic trajectory can be determined by analysing many of their online posts over time (Abiola et al., 2013; Taylor, & Pagliari, 2018). Similarly, patients in online health support communities face a dilemma of self-disclosure: while it is associated with negative outcomes, it is unavoidable in obtaining social support from other online health support community users.

While a large body of literature has contributed to a better understanding of online health support community users' disclosure patterns, current research is lacking in the following areas. Firstly, many previous studies relied on surveys or interviews to investigate users' privacy perceptions, which can sometimes fail to accurately reflect users' actual personal information disclosure behaviours in the real world, e.g., privacy paradox (e.g., Atanasova et al., 2018; Cavusoglu et al., 2016; Wu, Vitak, & Zimmer, 2020). Secondly, while user role (Wang, Zuo, & Zhao,, 2015a) is an important concept in online health support communities research, it is rarely considered when researching self-disclosure behaviours. Furthermore, the changing intentions of one's self-disclosure patterns in online health support communities are expected to be revealed by the dynamic nature of user roles. To address these gaps, this study adds a new construct of altruistic user role (AUR) to Fishbein and Ajzen's theory of reasoned action (Fishbein, & Ajzen, 1975; LaCaille, 2020). The chapter presents a conceptual framework developed from a data-driven computationally intensive review of literature for a study using a set of publicly available data from a peertopeer online health support communities designed for diabetic patients, using a mix of methods including manual coding, deep learning-based text mining techniques and econometric analysis. The implications of the proposed modified Theory of Reasoned Action are discussed.

BACKGROUND

TuDiabetes.Org PeertoPeer Online Health Support Community

To address the proposed research questions, this study focuses on TuDiabetes.org, a peertopeer online health support community for diabetic people and their caregivers. The advantages of utilising this online

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