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Social media as a space for support: Young adults' perspectives on producing and consuming user-generated content about diabetes and mental health

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ABSTRACT

Social media offer opportunities to both produce and consume content related to health experiences. However, people's social media practices are likely to be influenced by a range of individual, social and environmental factors. The aim of this qualitative study was to explore how engagement with user-generated content can support people with long-term health conditions, and what limits users' adoption of these technologies in the everyday experience of their health condition. Forty semi-structured interviews were conducted with young adults, aged between 18 and 30 years, with experience of diabetes or a common mental health disorder (CMHD). We found that the online activities of these young adults were diverse; they ranged from regular production and consumption ('prosumption') of health-related user-generated content to no engagement with such content. Our analysis suggested three main types of users: 'prosumers'; 'tacit consumers' and 'non-engagers'. A key determinant of participants' engagement with resources related to diabetes and CMHDs in the online environment was their offline experiences of support. Barriers to young adults' participation in online interaction, and sharing of content related to their health experiences, included concerns about compromising their presentation of identity and adherence to conventions about what content is most appropriate for specific social media spaces. Based on our analysis, we suggest that social media do not provide an unproblematic environment for engagement with health content and the generation of supportive networks. Rather, producing and consuming user-generated content is an activity embedded within individuals' specific health experiences and is impacted by offline contexts, as well as their daily engagement with, and expectations, of different social media platforms.

1. Introduction

Rapid developments in platforms that facilitate participatory internet activities have broadened users' opportunities for production and consumption of online content (e.g. Kaplan and Haenlein, 2010). Websites such as Facebook, Twitter, YouTube, blogs and wikis, collectively termed social media, facilitate many-to-many communication in contrast to traditional one-to-one personal communication and one-to-many media communication (Hawn, 2009). Since the mid-2000s social media have been widely adopted by users and become embedded features of contemporary life for many (Van Dijck, 2013). While the functionality and popularity of platforms may fluctuate, social media have become well established as sites for the presentation and management of identity (Papacharissi, 2010; Marwick and Boyd, 2011), the organisation of sociable practices (Boyd, 2007), and participation in community-based activity (Burgess and Green, 2009).

Health-related content has been a key feature of users' contributions to the online environment since people started to incorporate accounts of health and illness into personal homepages (Hardey, 2001). Social media allow for more convenient and widespread sharing of images, videos and comments related to health (McNab, 2009) and provide alternative resources for health information-seekers (Fergie et al., 2015). Ziebland and Wyke (2012) have identified seven domains by which people's health is impacted by the sharing of health experiences online (finding information, feeling supported, maintaining relationships with

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others, affecting behaviour, experiencing health, learning to tell the story, and visualising disease), all of which can be facilitated by various forms of social media. However, the importance of social media for users' health experiences is not always fully recognised. A recent review of policy documents on health and social networking sites suggests growing use of consumer-related marketisation rhetoric but a lack of recognition of the consistent role of social networking sites in facilitating peer-support and information sharing amongst people managing long-term health conditions (Hunt et al., 2015). Indeed, given the propensity for social media use amongst those experiencing chronic health issues (Fox and Jones, 2011), this group provides a key focus for developing a more nuanced understanding of the adoption and adaption of social media technology for the generation and exchange of health information.

‘Users’ have been variously characterised according to offline characteristics, such as social position and age. Some authors have suggested that online technologies exacerbate existing social inequalities, creating a ‘digital divide’ (Norris, 2001). Others have characterised young people as ‘digital natives’, a generation of internet users accustomed to the online environment (Tapscott, 1998; Prensky, 2001). Alternatively, Dutton et al. (2013) suggest five groupings of ‘users’ based on their perceptions of what the internet can provide for them, ranging from “enjoyable escape” to “problems” (p. 6). Nettleton et al.’s (2004) study presents a nuanced account of users' engagement with online health resources. The typology they suggest is based on relationship with the internet (problematic, episodic or domesticated) and form of reflexive engagement (instrumental or affective). This typology provides a useful starting point for understanding users' online practices. However, exploring people's practices in relation to user-generated health content specifically could offer new insights around contemporary internet use and engagement with health information.

In a recent UK survey of internet users, 25% of respondents reported accessing or sharing user-generated health-related content online. A minority of super-users (7.5%) acted as prolific contributors of user-generated content for others' consumption (O'Neill et al., 2014). The authors suggest two areas for further research: the activities of those who do not actively contribute health content but who consume content as “lurkers”; and the characteristics and requirements of a minority of internet users who reported no awareness of health-related user-generated content. To date, little research has explored the perspectives of these groups, or those characterised as “super-users” or “prosumers”, i.e. users who are engaged in the simultaneous processes of production and consumption (Kaplan and Haenlein, 2010; Ritzer and Jurgenson, 2010).

This study builds on previous characterisations of ‘users’ to explore engagement with health-related user-generated content in young adults with experience of long-term health conditions. Given the importance of exploring health-related social media use amongst those with long-term health issues (Fox and Jones, 2011; Hunt et al., 2015), we elected to focus on diabetes and common mental health disorders (CMHDs), such as depression, anxiety, panic and post-traumatic stress disorder (Nice, 2011), as exemplars. Entwistle et al., (2011) suggest that exploring experiences across a sample of participants with different health issues can enrich analyses because of the different information-seeking and decision-making challenges each issue presents. Diabetes and CMHDs involve different considerations for people in relation to: diagnosis, treatment options, information needs and decision-making. However, both involve some degree of self-management (Sterling et al., 2010). Moreover, both health issues have precipitated the development of high levels of user-generated content and vibrant online communities (Yonker et al., 2014; Hilliard et al., 2015).

Current research does not provide a detailed account of the ways that different social media platforms are experienced by people, particularly young people who increasingly use social media for social purposes and to engage with health content. Understanding current online practices is important for informing development of online health resources to support people's experiences of both diabetes and CMHDs. Current research also lacks exploration of the context of people's engagement with user-generated content and the barriers to contributing such content. This research was designed to explore young adults' experiences of consuming *and* producing health-related user-generated content as featured on popular social media sites, in the context of their day-to-day management of their health conditions. Our aim is to gain new insights into how people with long-term health conditions engage with user-generated content, and what barriers, if any, limit users' adoption of these technologies for supporting them in their health experiences.

2. Methods

Following a broadly interpretivist approach (Green and Thorogood, 2013), we used qualitative interviews to explore young adults' perspectives; similar methods have been used by others who have explored young people's social media use (Das, 2011). Ethical approval was gained from the University of Glasgow, College of Social Sciences Research Ethics Committee.

2.1. Sample

A purposive sample of men and women, aged 18–30 years, with experience of either diabetes or a CMHD, was selected for interview. Young adults were of particular interest to this study because of their life-stage and their potentially rich online experience. The life-stage of young, or ‘emerging’, adulthood has been identified as an important period of transition (Arnett, 2000), and ‘emerging’ adults as a group with unmet health needs (Marshall, 2011). Young adults (16–24 years) in the UK are also more likely to use the internet for social networking than all other internet users (83% of young adults visit social networking sites more than once a day) (Ofcom, 2014). Furthermore, in relation to the use of online support groups, a review of research on online communities for supporting experience of depression suggests most users were in their mid-20s to mid-40s (Griffiths et al., 2009). By identifying young adults as the population of interest, the focus of the study was narrowed to individuals who might share a common awareness of social media technologies.

Forty semi-structured interviews were conducted by GF between November 2012 and May 2013. Table 1 contains information on participant characteristics. The sample was designed to include similar numbers of men and women and similar numbers of people with experience of diabetes and CMHDs to allow exploration of differences and similarities between these sub-groups.

Participants were recruited both offline and online (see Table 1). In order to specifically target young adults, information about the study was displayed in further/continuing education institutions (offering basic skills training and vocational qualifications) and higher education institutions (offering degree level qualifications). Gatekeepers working in organisations which support young adults with diabetes or CMHDs also distributed study information to potential participants, and some participants recommended the study to their peers. Study information was also posted online in Facebook groups and forums for discussion of diabetes or CMHDs.