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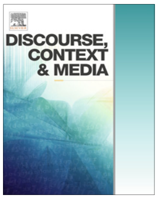

# Dementia on Facebook: Requesting information and advice about dementia risk-prevention on social media

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ABSTRACT

Social media platforms like Facebook have the potential to make significant contributions to health communication and promotion, yet little is known about the social practices that routinely occur in such spaces. Health organisations can use social media to communicate about public health issues like the prevention of dementia for the purpose of improving population health outcomes. In this study, we examine posts on a conversation on a Facebook Page about dementia risk and prevention activity moderated by researchers affiliated with a prominent Australian dementia organisation. The analysis illustrates how posts in the conversation routinely functioned to make relevant and manage accountability and identity, and position users as responsible for risk-management. Understanding more about social norms of communicating about dementia risk-prevention online can provide insight into how posters experience and understand the issues of cognitive ageing and dementia, which may inform future tailored health communication strategies using social media. This is of significance given the increasing prevalence of dementia worldwide, and the growing importance of social media as sources of health information.

## 1. Introduction

With population ageing proceeding at an unprecedented pace worldwide, dementia presents a major public health concern. Substantial research effort has gone into identifying risk factors and developing lifestyle-based interventions to prevent or manage the condition. Social media platforms provide unique opportunities to examine how dementia is represented online, yet few studies have focused on the social practices that routinely occur in such spaces, including how users attend to matters of accountability and identity. In addition, little is known about how health organisations and members of the public collectively construct understandings of cognitive decline and dementia on social media. Developing understandings of how communication about dementia is structured on social media may be an important step in developing strategies to support effective and appropriate communication in online spaces.

### *1.1. Facebook and health communication*

Social media and social networking sites (SNSs) are recognised to be important channels for communication between researchers, health agencies, and organisations, and for the delivery of health promotion information to clinical and non-clinical populations (Bender et al., 2011; Prestin and Chou, 2014; Zhang et al., 2013). Facebook is the most popular SNS worldwide, attracting approximately 2.07 billion active users monthly as of September 30, 2017 (Facebook, 2017a). Facebook provides a platform for the creation of highly visible networks of social interaction that can be traversed by users. Although people below 30 years of age are most likely to use Facebook, the fastest growing demographic is claimed to be those over 65 years of age (Jung and Sundar, 2016). Unlike health-related Facebook ‘Groups’, which are typically created by individual users for the purpose of small group discussion, Facebook ‘Pages’[1] are public profiles that represent the official voice of companies, organisations, campaign groups, or institutions (Facebook, 2017b). Official representatives can manage the content published on Pages, which is available for public consumption and discussion. It has been argued that organisations might be able to use their official Pages to accomplish particular organisational goals,

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[1] In this study, we use ‘Group’ and ‘Pages’ to refer to Facebook-specific uses of the terms.

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such as education and health campaigning, as well as the commercial practices of marketing and advertising (e.g., Hunt and Koteyko, 2015; Park et al., 2011; Thurlow, 2013). As Thurlow (2013) suggested, organisations can use the personalised and informal interactional style that distinguishes Facebook communication to blur the boundaries between public and private discourse, thereby maximising audience appeal. Given the potential of Facebook as a platform for impactful communication between health organisations and the general public, research is needed to extend current understandings the social practices that take place such spaces. Research into the social norms of communicating about health and illness on Facebook can provide insight into users' understandings and experiences of major public health issues like dementia. Such insight may used to inform future health communication efforts to increase engagement with health information, and promote greater participation in support groups, screening, and lifestyle programs.

### *1.2. Social media use and dementia*

Little is known about how the health issues of cognitive decline and dementia are represented on SNSs, although previous research has examined newsprint and broadcast media coverage of these topics (e.g., Kang et al., 2010; Kirkman, 2006; Peel, 2014; Van Gorp and Vercruysse, 2012). To our knowledge, only one study has examined peer-to-peer discussions about dementia on Facebook. Facebook Groups for people living with early-onset dementia were described as providing peer support, raising community awareness, and reducing social isolation (Craig and Strivens, 2016). As has been shown in relation to breast cancer (Abramson et al., 2015) and diabetes (Hunt and Koteyko, 2015), individuals, health professionals, and organisations can use Facebook Pages to share information, opinions, and advice.

Recent analyses have highlighted that advice pertaining to prevention of cognitive decline and dementia is common in newsprint media (Lawless & Augoustinos, 2017; Peel, 2014). Such advice routinely takes the form of recommendations to participate in lifestyle practices (such as diet, physical exercise, and cognitive stimulation) that are claimed to improve neural connectivity and reduce the risk of developing dementia. Although information about risk and prevention can be regarded as empowering, it has been argued that such representations may also contribute to the promotion of a potentially repressive neoliberal discourse of self-responsibility and self-control (Peel, 2014; Pitts-Taylor, 2010; Williams et al., 2011). In this neoliberal discourse, participation in health-promoting activities becomes a moral obligation, and individual health and wellness is presented as a matter of exercising self-control in relation to various lifestyle choices and practices (Crawford, 2006; Lupton, 1995; Nettleton, 2013).

Digital technologies and social media may contribute to the reproduction of neoliberal health discourse by providing new opportunities for promoting participation in self-care and self-monitoring practices (Lupton, 2012, 2013). Such concerns are relevant to the notion that healthy individuals can be positioned as 'patients without symptoms' (Finkler, 2000): that is, as responsible for participation in risk management to prevent future illness. Such 'at-risk' positioning can be accomplished via the dissemination of information about appropriate self-care practices or risk factors, such as age and genetic susceptibility. Komduur and te Molder (2014), for example, argued that reference to notions of genetic susceptibility and family history (i.e., the notion that a condition 'runs in the family') are routinely presented as justification for 'health consciousness' and participation in healthy behaviours as a form of risk prevention. Genetic susceptibility may be a significant factor in estimates of individuals' risk of particular conditions, including types of dementia (Lock et al. 2006). People have been shown to draw on notions of genetic predisposition to negotiate personal responsibility and blame for illness by emphasising a lack of control over the development of particular conditions (Crossley, 2002). In addition to awareness of family history, people's capacity to self-monitor, recognise, and evaluate their symptoms can be regarded as central to the management of risk and the self-care of minor and chronic conditions.

### *1.3. Advice giving in computer-mediated communication*

Several studies have used discursive and interactional approaches to examine health-related content on digital platforms, including online discussion forums, e-mail, instant messaging services, and social networks (e.g., Giles, 2013; Horne and Wiggins, 2009; Locher, 2006; Smithson et al., 2011; Sneijder and te Molder, 2005; Stommel and Koole, 2010; Vayreda and Antaki, 2009; Veen et al., 2010). These studies highlight the social nature of computer-mediated communication, concentrating on the interactional work that participants accomplish in particular digital environments. Studies of online support groups (OSGs), in particular, have focused on the interactional concerns that participants make relevant in their contributions, including the management of accountability[2] and identity. In addition, a number of studies have examined how participants request and deliver advice in such contexts (e.g., Morrow, 2006; Sneijder and te Molder, 2005; Stommel and Koole, 2010; Vayreda and Antaki, 2009; Veen et al., 2010). Requests for advice are routinely presented in complex and indirect ways and serve to perform a range of interactional tasks, such as demonstrating adherence to norms of the online community, managing accountability, and constructing identity (Burke et al., 2010; Stommel, 2009; Vayreda and Antaki, 2009). Requests for advice and information about particular health-related topics (e.g., self-harm, depression, and eating disorders) have also been to shown to involve accounts of relevant personal problems (Lamerichs and te Molder, 2003; Morrow, 2006; Smithson et al., 2011; Stommel, 2009; Stommel and Koole, 2010). Likewise, advice provision in such environments often involves offering an account, or packaging the advice in particular ways, in order to make the advice acceptable to the recipient.

Although comparisons can be made with OSGs and various types of Internet question and answer platforms (e.g., 'Yahoo! Answers'), interaction between users on Facebook Pages is different from that on many online communities. First, OSGs and many professionally moderated sites generally provide forums for anonymous discussion, whereas Facebook, and other sites that involve the creation of a visible user profiles, constitutes a non-anonymous setting. Second, while OSGs are typically private groups that are established and managed by non-professionals who share similar experiences or interests, companies and organisations tend to administer Facebook Pages. Like OSGs, Pages may be used to exchange information and social support. Unlike OSGs, however, organisations may use Pages for the purposes of advertising, campaigning, and promotion. Although activities relating to joining and maintaining online communities may be less important on Facebook Pages than in private groups, comparisons can be made with anonymous Internet forums in terms of relevant activities like the sharing of personal problems, requesting advice, and giving advice, which can contribute to legitimising participation in such environments.

Research into how health communication on Facebook Pages is structured can provide insights into the interactional work

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[2] In the context of online forums, 'accountability' can be characterised broadly as an orientation to normative expectations regarding conduct and self-presentation. Matters of accountability in online forums include managing the legitimacy of posters' claims or the factual status of descriptions. This type of accountability has been described as the concern 'forumability', which involves displaying the various normative requirements for the assistance being sought in the online context (Stommel, 2009).

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