

**Harnessing Facilitated
Digital Health Communities
to Support Empowerment of
Informal Carers of People
with Mental Illness:
Effect of Enablers and
Inhibitors**

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Certificate of original authorship

I, Tsholofelo Jacqueline Sethibe, declare that this thesis submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Information Systems), in the School of Professional Practice and Leadership in the Faculty of Engineering and Information Technology at the University of Technology Sydney.

This thesis is entirely my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Abstract

The utilisation of digital health communities (DHCs) generates support, advice, and information, which have the potential to empower users – patients or carers, who join a digital health community for support. Empowerment is important because it enhances one's self-directed ability to cope with challenges, make informed decisions and mobilise needed resources to help users to regain a sense of control in their lives. This research contributes to the information systems (IS) body of knowledge by proposing and theorising the concept of empowerment for decision-making in digital health communities.

Despite the potential, it is not clear how digital health communities foster the empowerment of carers. It is also not clear how systematic professional facilitation, which some digital health communities utilise to combat information overload and asymmetry, affects empowerment. To address this lack of understanding, this study aims to investigate what constitutes empowerment, what support exchanges are generated by the digital health community use to empower, and what role is played by facilitator support in the empowerment of users. It draws empirical insights from a less-explored digital health community of informal carers of people with mental illness, based in Australia. It engages a mixed-methods approach (exploratory sequential design) to collect and analyse data from IS experts in interviews, carry out a content analysis on 3000+ messages, and conduct a web-based survey of informal carers. The inquiry is done through the theoretical lens of the empowerment theory.

The key findings of this study are (a). social support and experiential expertise are good predictors of carer empowerment (b). empowerment in a digital health community has an affective dimension in addition to intrapersonal, interactional and behavioural dimensions (c). the type of facilitator presence (collaborative, commanding, motivating) contributes to the carers' ability to make health-related and other decisions (d). facilitator support has a moderating effect on social support and experiential expertise. The findings also provide foundations for further investigation into empowerment, in particular, how to foster it for improved decision-making in digital health communities and other contexts.

Some contributions the study makes include, 1. extending the traditional empowerment theory and its application in the context of the digital health community, enabling theorisation of dual effects. 2. contributing further to understanding empowerment for decision-making. This is because most studies mentioning empowerment in digital health communities are on treatment adherence or doctor-patient relationship (Table 2.2). 3. contributing methodological skill, where the study involved the use of three phases of investigating a sequential, mixed-methods design.