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Exploring the use of mobile information and communication technologies by people with mood disorders

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(i) Abstract and key words

Information and communication technologies (ICTs) have become increasingly integrated into how care is delivered and received. However, no research has yet explored how people with mood disorders use mobile information and communication technologies (mICTs) in their everyday lives and, more specifically, how they might use mICTs to look after themselves. An exploratory qualitative study, within secondary and specialist mental health services, was undertaken. Data generation involved in-depth, semi-structured interviews with 26 people with mood disorders. Participants' datasets were analysed using Constructivist Grounded Theory (CGT). The resultant theory explains how mICTs were used in daily life, and also, more specifically, how they were used to manage recovery from mood disorders. The findings reveal that people with mood disorders used their mICTs to centralise themselves within their on-and-offline worlds and their importance of attachment were central in their continued use. These findings have the potential to inform and encourage the further incorporation of mICTs into the health and social care settings; spanning the therapeutic to systemic levels so that the full potential of these ubiquitous technologies can be harnessed to improve care and care delivery. Yet, without adequate resource and support, health and social care professionals' efforts will be hampered, contributing to technology redundancy and high attrition rates in the use of this type of technology.

Key words: *Qualitative research; mental health; mood disorder; mobile information and communication technology*

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(ii) Text

Background

Globally, one in five adults will have experienced a common mental disorder within the past 12 months and 29.2% experience a common mental disorder at some point during their lifetime (Steel et al., 2014). Within Europe, mental health issues account for nearly 40% of all years lived with disability, with depression being the leading long-term condition (at 13.7%) of the disability burden (The Scottish Government, 2012). With mental health, especially depression and other mood disorders being a major public health concern (Knowles et al., 2014), the development and use of new technologies that may improve treatment accessibility, improve patient education, enhance retention of people within services, and reduce stigma are of critical importance (Ehrenreich et al., 2011). EHealth is an umbrella term encompassing all forms of information and communication technology used for direct patient care, such as the use of the Internet or computer technology and electronic systems (Eland-de Kok et al., 2011). EHealth can facilitate the delivery of a wide range of effective treatments for mental health problems and have led to an increase in the choices available to patients for selecting an approach best suited to manage their long-term condition (Eland-de Kok et al., 2011). Such choices include: computerised cognitive behavioural therapy (cCBT) (So et al., 2013); computerised bibliotherapy and online self-help resources/patient information websites (Dolemeyer et al., 2013); online counselling (Griffiths, Farrer, & Christensen, 2010); patient forums, blogs, social media/social networking sites (Pulman, 2009) and online self-management groups (Cooper, 2013). MHealth, defined as *“medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices (World Health Organisation, 2011) (p.6)”* has captured the use of mobile telecommunication and multi-media technologies for the delivery of health and health services. Mobile technologies may mitigate access challenges in relation to receiving timely and appropriate

mental health care in that they can connect the user to information and support resources (Tomlinson et al., 2013). However, it is not well understood if and how people with mood disorders use mobile technologies in their daily lives and what their applicability may be for managing health and wellbeing (Fulford et al., 2016). This information is vital to reduce technological attrition and redundancy (Poole, 2013). The aim of the study was to understand why and how people with mood disorders used mICTs such as mobile phones, smartphones, tablet-PCs and laptops in their everyday lives, and also, in their recovery from mood disorder.

Design and Methods

The study was based on a cross-sectional exploratory design involving semi-structured interviews with people with mood disorders in the North East of Scotland. The data collection period was from April 2015 to March 2016.

Recruitment and sampling

People with mood disorders were identified by health and social care professionals who provided mental health services to them. Participants with mood disorders were provided with a participant information sheet by their professional at least 24 hours prior to interview. This provided an opportunity for participants to ask questions before written informed consent was taken at time of interview. This was undertaken by the first author (HF) who is experienced in assessing capacity and verifying that participants understand what they are taking part in and what was being asked of them. Selection criteria is provided in Table 1. Interviews were conducted with participants in a place of their choosing, using a topic guide to facilitate the interviews (Table 2). A practical, maximum-variance sampling strategy was used in the first instance with participants purposefully chosen to maximise the opportunities to gather data.

The sample was defined in advance and healthcare practitioners were informed of recruitment quotas and regularly updated on the progress of recruitment. There was potential for bias in the sample selected by healthcare practitioners however, the research was focused upon mobile technology use rather than patient care which may have helped mitigate this effect. Theoretical sampling was used to refine concepts and categories. Theoretical sampling is the process of data collection for the generation of theory where data are collected, coded and analysed concurrently and used to inform subsequent rounds of data collection to further refine categories and emergent theory (Strauss & Corbin, 2008). The study utilised concurrent interviewing, transcribing, analysing and theorising. To manage this process, interviews were completed in batches; after completing the data analysis for the first batch of interviews, there was a requirement to assess the emergent theoretical categories. Coding portrayed the meaning construed from the data; resonating through open, focused, and higher-ordered constructs as coding became increasingly analytical and conceptual. The first batch, therefore, provided an analytical framework to guide future interview questions and theoretical sampling. Data were analysed after each interview and in batches, informing the next interview and creating an iterative and reflective process while respecting the chosen methodological approach. Data collection and analysis continued until theoretical saturation had occurred. The researcher knew theoretical saturation had been achieved when no new categories emerged and no further variation within categories took place. Grounded theory involves the gradual identification and integration of categories of meaning from the data, and the identification of relationships between them (Spencer et al., 2014; Willig, 2013). As the generation of a theory is essentially never-ending, theoretical saturation was seen as a goal rather than reality (Willig, 2013).

Ethics

In addition to Sponsorship approval, a favorable ethical opinion was obtained from the appropriate NHS Research Ethics Committee (15/ES/0022), and appropriate NHS Research & Development (2014MH16) approval was obtained prior to the commencement of the study.

Data management and analysis

All interviews were recorded by digital recorder and subsequently transcribed verbatim and analysed by the first author (HF). NVivo10 was used for data management purposes which is a type of computer-assisted qualitative data analysis software (CAQDAS) available to support qualitative research. The software provided a digital, single storage area for information, such as transcriptions, coding, memos and demographic data. Due to the digital nature of the information, sharing data analysis was straightforward, facilitating transparency and rigor as any coding issues could be viewed and discussed collectively (HF, LMc, SMc & TK) until resolved. Data from participants were analysed in accordance with Constructive Grounded Theory (CGT) methodology using open coding, focused coding, constant comparative process, memo writing and theoretical sampling, saturation and sorting (Charmaz, 2014). Grounded theory coding creates an analytic frame, facilitating analysis by connecting segments of data with the analytic abstractions placed upon them. Open coding breaks the data apart, deriving and developing concepts for each word, sentence or segment of data. This process creates the basic descriptive codes, forming the beginning of meaning from the data. Focused coding uses frequently appearing open codes to crosscut and relate concepts to each other, allowing the sorting of large amounts of data so that categories can emerge (Cummings & Borycki, 2011). A constant comparative approach was used to determine similarities and differences between emerging categories (Corbin & Strauss, 2008, Cummings & Borycki, 2011, Willig, 2013).

Findings

This section provides an overview of the sample of participants achieved before moving on to illuminate the findings by presenting the main theoretical finding 'Centrality through interconnectivity', and its three theoretical sub-categories 'Outsourcing of needs', 'Management of needs' and 'Disconnection of communication'. A theoretical model is conceptualised in Figure 1. The findings present information on how mICTs are used by people with mood disorders both in their everyday lives, which may have similarities with the general population, but also, more specifically, their use for the recovery from mood disorder.

Sample characteristics

Twenty-six people with mood disorders (Table 3) were interviewed. Ten males and sixteen females were recruited across an age range of 18-56+ with the majority falling in the 26-55 year-old age range. All participants were recruited across the selected NHS area from both urban and rural localities.

Centrality through interconnectivity

Social relationships and how people used mobile technology to communicate with each other or share information were participants' principal concern. Centrality through interconnectivity can be defined as; the act of remaining central within the exchange of information and central to the attachment towards the technology. MICTs facilitated people to remain at the centre of their on-and-offline worlds through managing their access to information. Their relationships with mobile technology appeared to be on continua of use. At one end, their use of mICTs was of central importance in terms of the feelings of attachment and importance they placed upon these objects. Evidence of this was demonstrated by how people described having feelings of attachment towards them:

I can't do without my phone I sleep with it under my pillow. Well it's like my friend, you know, it is my lifeline. It's like my pal, you know I'd be lost without my phone. I mean I lost it the other day and I didn't have a landline to phone my phone to see where it was so I was going mad in the house because I couldn't find my phone and I had to do without it for like half an hour and I felt like I was going to die because I didn't have my phone.
(Gail)

Conversely, technology could be a small component in participants' lives, both in its importance and societal reach. Participants, at times, chose either not to use mICTs at all or to downgrade the functionality of the technology. This purposefully limited their access to interconnectivity, thereby removing them from a sense of information overload, lessening the demands placed upon them when using the technology.

MICTs enabled individuals to connect with friends and family through email, telephone, video-chat, text message, instant messaging and social networking sites. Social support could be given and received. If required, mICTs offered immediacy to things, whether that was the retrieval of information on the Internet, or communication with others. Therefore, mICTs offered connectivity between self and society. Clients had to learn new skills and practices, such as online etiquette, managing risks, and utilising the benefits that mICTs afforded them. The grounded theory approach helped understand how participants with mood disorders made use of their mICTs in their daily lives (macro-level understanding), and also, how they used mICTs specifically to facilitate their recovery from mood disorders (micro-level of understanding).

Outsourcing of needs

MICTs provided a means to access, meet and outsource certain needs; whether these were basic needs (online shopping, organising finances online), psychological needs (attending to relationships online, facilitating accomplishing stages of recovery), or self-fulfilment needs (digital meditation, yoga, online creativity). MICTs had become convenient utilities for people as they could be placed next to them on the sofa, their bedside table or in their pocket when outside. Their un-intrusive and location-independent features enabled individuals to gain a certain mastery over their environment in order to meet their needs. For people who had difficulty telephoning people, MICTs offered an easier alternative, for example, through text, email or instant messaging. This transformed something that was potentially stressful, into something convenient, which was easy to use:

Normally if I'm on the phone I'll normally text people. If I don't know the number on my screen I won't answer it, I normally do most of my communication through text or email. I very rarely do phone-calls. (Kate)

The detached form of communication and connectivity enabled people to have the choice and control over whether to delete and/or block problematic users. Also, having a digital record of communication was valuable if evidence of online abuse was required:

It [smartphone] helps because I had to get the police involved. If it was said face-to-face, it was one person's word against the other's. I could physically show them the text so he obviously got in a lot of bother for that so I think phones are a lot safer. (Candy)

The MICT essentially became an emotional shield for some participants, filtering out what they did not want another person to see or hear, but still facilitated communication in a tailored manner. Some felt they were being judged less by others when using online written forms of

communication. MICTs provided a sense of choice and control in their lives; they could choose their medium of communication, and, importantly, decide whether they wished to communicate, and, if so, they could control the digital environment.

Management of needs

People used their mICTs as a tool to support self-management. However, rather than using specific mood disorder related software, they used mICTs to help look after themselves in more intuitive and, at times, accidental ways. MICTs provided participants with the interconnectivity required to attend to pre-existing social ties and form new relationships. Therefore, mICTs had the ability to place people in the centre of their social world, becoming a utility central for fulfilling their needs. Being able to access social support through mICTs offered a sense of reassurance. This was achieved by being able to contact trusted others, wherever they were, at whatever time of day, through the interconnectivity that mICTs offered in order to receive or provide help:

I can contact people I know I can trust and for support, particularly my sister. She often leans on me as well when she's struggling and you know we talk to each other or Facebook message her an awful lot and when something is going badly or you're struggling with something it's good to, wherever you are, to be able to have that connectivity to somebody that can help. (Brian)

MICTs increased the possibilities to seek and/or receive support when arguably they required it most:

It's my only contact with people when I'm having a really bad bout of depression, I'm not obviously leaving the house. If I had a normal phone, I wouldn't have any contact with

people. My phone's pretty much my life. I live on my own and I don't have a job just now, I don't have Wi-Fi, so I'm quite reliant on just my phone. (Candy)

As mICTs were increasingly used, relied upon and infused with importance; people appeared to gradually embed them into their lives. MICTs have become established in society, along with the acceptance of certain behaviours associated with their use:

It slowly became something that you used all the time over the years. (Brian)

However, there was evidence of some contrast in terms of attachment, demonstrated by some participants' mICTs having gravitated towards the periphery of their lives. Mobile technology for them was less central; there was a sense of peripherality, and they appeared to be less attached to the functionality and usability that the technology offered. That being said, most people regarded their mICTs as successfully fulfilling varying functions and uses to enable them to self-manage:

Oh most definitely a way of keeping in contact with people without actually having to leave wherever you're feeling comfortable at that time. It's your friend, your family, your professionals, there's a link to everything when you don't feel that you can deal with that. Your Facebook will bring you a smile, YouTube will bring you a distraction, phone conversation with a friend will bring you a bit of relief. But to have to go out and seek that out might be much harder task than having it in your pocket. (Greg)

Participants described using their mICTs in a variety of ways to perform self-care behaviour, including, but not limited to; distraction, health and fitness, supporting talking, symptom management, music, and the use of apps:

I use it for Facebook, online banking, research, I look up various things. Sometimes I look up medication or I look up side effects of this new diagnosis and things like that. Sometimes use it for contacting Samaritans. Game playing; Farmville, Royal Story, a game called Odd Socks. To occupy my mind so that my thoughts aren't racing through my head. You're not thinking of your unhelpful thoughts you're concentrating more on what's going on in the game. (Sarah)

MICTs facilitated access to information on mental health to help them understand their conditions, their medication and approaches to recovery. MICTs were used to access online support forums, places where people could talk to others with similar experiences, which helped them to feel better. Advice from peers was viewed as being more genuine than that provided by professionals. Individuals acquired new knowledge about mood disorders from existing posts and posted their own queries, helping them to learn new coping mechanisms. Reading posts from other people who were going through difficult experiences helped put things into perspective.

Having this link to Services and support encouraged participants to continue with their recovery; as compared to others who did not use mICTs as comprehensively, they felt in a better place. Being positive for someone else on an online support forum helped some people feel better about themselves. Therefore, accessing online support forums through mICTs provided them with a survival tool and enabled people to source local community resources and opportunities to help look after themselves.

Disconnection of communication

There was a clear disconnect in the communication and use between participants and the health and social care professionals they had contact with. Participants recognised a digital disconnect regarding the sophistication of mICTs they used in comparison to those of their professionals. They also recognised the incompatibility between them both in terms of desired capabilities and communication options. The way Services were designed to communicate appeared unhelpful for some people as they could find it difficult to talk on the telephone. Reasons for this included; feeling judged, feeling under pressure, and not having enough time to construct what they wanted to say due to the immediacy of talking when on the telephone:

I hate the telephone, particularly now, I hate having to talk to people on the telephone. You just don't get any or enough feedback; how they're feeling, how they're reacting to what you say, I just find it horribly impersonal. Written or text is impersonal but I can be precise with it. It's the language that's used, I'm more able to express myself because I'm not kind of rushing to get things in. (Cal)

Having communication options was important to inform health professionals about their wellbeing, or the need for emergency help. The apparent rigidity, inflexibility and unawareness of client communication needs by Services reduced the person-centeredness of the organisations. A desirable functionality which could be offered by Services was a digital record where people's daily thoughts, feelings, emotions and behaviours could be written down, stored and accessed. Due to participants being digitally disconnected this affected the ability of Services to support their self-care, self-management and the delivery of self-management support to people with mood disorders. The data points to participants' needs being unmet, whether wholly or partially, as a result of their mood disorders and it appears that they used mICTs to try and meet their unmet needs with varying levels of success. Participants who

participated in the research project were at different stages in their recovery from mood disorders, and these themes and usage patterns were represented in their stories of recovery. Exploring how participants with mood disorders made use of their mICTs provided an understanding towards their uses, challenges and benefits in their recovery.

Discussion

The application of mobile technologies in mental health treatment has not sufficiently explored the nuanced experiences, expectations and challenges people with serious mental health issues face when trying to make practical use of such technology (Chiauzzi & Newell, 2019). The findings of our study are of particular relevance to mental health nursing as it provides for the first time an understanding of how people with mood disorders make use of their mICTs. Our study has highlighted how mICTs are now embedded into the lives of people with mood disorders and furthered our understanding of their ubiquity, mobility and accessibility that mICTs offer people; mICTs are likely permanent fixtures in our world, viewed as ubiquitous, and their ownership, usability and functionality perceived as a need. This understanding will hopefully be of benefit to mental health nurses to help harness the potential of mICTs for recovery and mitigate the challenging effects of their usage.

The design of many existing eHealth and mHealth interventions have been based on pre-existing health care system constructs and designed using the assumptions of experts regarding what end users require, leading to less effective and more compromised interventions (McCurdie et al., 2012). Human Computer Interaction (HCI) and User Centred Design (UCD) theory are two approaches that have been used in the design of mICTs. The many complex, multi-faceted, socially based phenomena within HCI and UCD research can be difficult to quantify or experimentally manipulate making the process of defining variables for quantitative research

very difficult (Adams et al., 2008). HCI and interaction design research has increasingly turned to qualitative methods in order to explore users' thoughts and feelings regarding technology, its overall potential, and how mobile technology forms part of wider human activities (Kaptelinin, 2006; Klasnja et al., 2011). Our qualitative CGT study provided a mechanism with which to analyse usability within complex socio-ecological systems and viewed patients as the end-users of technology; whether they used mood disorder specific applications or utilised their mICTs in more generic ways for managing their recovery. This included exploring the nature of HCI and interaction design phenomena, such as user engagement, satisfaction, privacy and trust. Our findings recommend the use of co-creation methods for the successful involvement of all stakeholders in the future design of mICTs; incorporating collaborative, context-sensitive, interactive and socially engaged approaches (Battersby et al., 2017).

The key finding of the study was the theory of Centrality Through Interconnectivity and the identification that mICTs have been interwoven by participants into their on-and-offline web of social and physical lives. As mental health is a key health improvement target and an area where services are often overstretched accessing online resources to facilitate self-management has the potential to be widely effective (Karasaouli & Adams, 2014). Our study identified that mICTs were being used as a resource enabling a sense of control within participants' lives, providing them with the opportunity to access information to help themselves, increase their understanding of when to seek help, and increase their awareness of what help was available. Participants acquired knowledge through mICT use and gained a sense of power through feeling more in control of their lives as a result. This was demonstrated through the evidence gained from their discussions regarding the importance of being able to search the Internet for answers to health-related questions, re-engage with their community, self-manage through self-identified strategies, and access Services in ways that were helpful to them. Participants enhanced their diversity of self-care practices through increased familiarity with the Internet

and the necessary skills for using it. Other control behaviours facilitated by mICT were: being able to see who was calling and to decide whether to answer the phone or not; being able to decide whether to reply or send a text message (control and a cathartic process); and whether to accept or delete relationships online.

The dynamic of the therapeutic relationship can appear to change when it moves from the offline to the online setting (Mercer et al., 2012; Clarke et al., 2016). Our study further explored this change in relationship features and conceptualised the common processes that characterised relationships in the online environment. Of importance was the egalitarian nature of the online communication medium and the choice and control it provided to participants. At a relational level there appeared to have been movement in the power dynamic between client and professional; participants were outsourcing their needs through their mICTs, meeting their needs when and how they wanted, with less reliance upon traditional systems of support. However, similar to findings by Vis et al. (2018) there were clear disconnections in communication between people with mood disorders and their Services, and disconnection faced by practitioners due to being behind in the adoption of up-to-date technology. This study identified that participants with mood disorders both sought and received support through their use of mICTs, often facilitating their first steps towards managing their recovery after periods of deliberation however, user-related, health-related and technology-related barriers are still required to navigated and negotiated (Simblett et al., 2019). Whilst the CGT approach conceptualised similar influencing factors as Fulford et al. (2016) in terms of why people with mood disorders chose to use ICTs such as their affordability, accessibility and versatility; it also theorised new ones, such as power (facilitate choice and control), safety (sense of attachment), and fulfilment (informational needs met).

MICTs have the potential to deliver digital mental health interventions with precision dependent on the stage of a person's recovery from mood disorder (Lipschitz et al., 2019; Rubanovich et al., 2017; Vis et al., 2018). However, our study identified that most participants did not use mood disorder specific mHealth interventions (apps, websites) for similar usability reasons as discussed above. Instead, it appears mICTs were used by participants as part of their wider human activities to manage their mood disorders. For example, they used online social networking sites for social support, (online) gaming for managing intrusive thoughts, yoga or meditations apps to reduce anxiety and stress, or when going out in public was too difficult, they used their mICTs to access the internet to bank, shop and meet their information requirements. Whether mICTs are used to deliver precision interventions or form part of peoples wider human activities to manage mood disorders; bridging the digital divide between Services and patients is vital so that mICT usage can be incorporated within mental health assessments, and with that, their possible inclusion within care planning (Chan et al., 2017).

Study Limitations and Strengths

There are several limitations to the study. The in-depth primary study had inclusion criteria demanding that participants were able to communicate in English and this may have limited the findings of the research, in terms of multi-cultural aspects and differing worldviews. This is an important limitation as mICT use is likely to be different depending on the cultural setting as well as IT infrastructures, resources, and health systems governance arrangements. The use of healthcare practitioners as gatekeepers could potentially have introduced bias into the sample although steps were taken when preparing practitioners to mitigate this occurring. There is potential for findings to become dated however, mobile telephones, smartphones, laptops and

tablet-PCs, and the software used or accessed through them, such as websites, forums and apps, will be upgraded, but a paradigm shift in technology is unlikely. Therefore, the theory created by this study could become a helpful tool for nurses and healthcare professionals to understand and harness their use to assist in people's recovery. The exploratory nature of the study and its geographical focus could also be viewed as limitations. Despite these limitations, this is the first study that has explored how people with mood disorders use mICTs.

Conclusion

To date, there has been a paucity of research underpinning the development of mICTs and their implementation in relation to people with mental health conditions, particularly mood disorders, and, perhaps, more focus is needed in this area for future research. As such, it was important to understand the ubiquity, mobility and accessibility that mICTs offer to people with mood disorders; mICTs are likely permanent fixtures in our world, viewed as ubiquitous, and their ownership, usability and functionality perceived as a need. This research diverges from the topics of the most published research on ICTs and health. That is, rather than concentrating on the micro-level, such as specific websites and apps, our research has endeavoured to focus the lens upon macro-level understanding. The resultant research has, both, explored and explained how mICTs are embedded into the lives of people with mood disorders.

Relevance for clinical practice

The study has created an empirical basis to help guide and harness the potential that mICTs hold for delivering self-management and self-management support; thereby facilitating collaborative person-centred care to support people in their active recovery from mood disorders. More importantly, it will guide the incorporation of mICTs into the therapeutic setting and inform clinicians and services how best to harness the technology to support people's recovery. It is

anticipated that this research offers the knowledge and insights necessary to bridge the digital disconnect; thereby enabling the full potential of mICTs to be managed and utilised by people with mood disorders, and inform and encourage the use of such technology by their health and social care professionals.

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