

Research Proposal: Qualitative investigation into Internet-based Interventions for Professional Dementia Caregivers' Wellbeing

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Abstract

This paper proposes a qualitative investigation into internet-based intervention for the wellbeing of professional dementia caregivers. Dementia care is associated with care burden leading to negative psychological consequences, such as stress, anxiety, and depression. The coronavirus disease (COVID-19) has made access to the traditional face-to-face therapy challenging for dementia caregivers. Accordingly, some dementia caregivers have started to use therapy via information and communication technologies (ICTs) including internet-based interventions. The interventions offered in this medium include cognitive behavioural therapy (CBT) and psychoeducation. To date, research has only examined the effects of these ICTs interventions among informal/family dementia caregivers, suggesting a need to examine the effects on professional dementia caregivers. In order to capture their first-hand experience receiving ICTs interventions on wellbeing, a qualitative research, using thematic analysis on semi-structured interview is proposed. Interviews will focus on the strengths and weaknesses of ICTs interventions on their mental wellbeing and care burden. Findings can inform the utility of these interventions for professional dementia caregivers in COVID-19 to help protect them from severe mental distress such as burnout supporting long-lasting care for their patients/clients.

Keywords: *Qualitative investigation; Internet-based; ICTs; CBT; Psychoeducation; Interventions; Professional dementia caregivers; COVID-19; Research proposal*

Introduction

There has been a steady increase in life expectancy due to improvements in medicine, science, and technology (Weatherall et al., 2006). One of the several

factors leading to dementia is ageing (Chen et al., 2009) and the population of aged people continues to increase with a resultant increase in the cost of caring for this ageing population (Papadopoulos, 2020;

Wittenberg et al., 2020). New report shows that the number of people with dementia is going to double by 2050 (Health Europa, 2020). Consequently, caring for this population group becomes challenging to dementia caregivers who suffer physically and psychologically from care burden (Hsu & Willis, 2013). There is significant amount of stress as a result of care burden from dementia caregivers' caregiving role where gender and educational background are some of the risk factors (Adelman et al., 2014; Cheng, 2017; Yu et al., 2015). Dementia caregivers are faced with significant physical and psychological challenges. The caregiving roles of dementia caregivers stretch across the whole day as they work round the clock and consequently, they are isolated (Adelman et al., 2014; Yu et al., 2015).

The wellbeing of dementia caregivers is expected to be challenged in the unprecedented time of the coronavirus (COVID-19). A recent study noted that people with dementia and their caregivers are seriously affected by the lockdown and isolations (Wang et al., 2020). Dementia caregivers suffer from care burden which negatively affects their quality of life (Igarashi et al., 2020). Stress, anxiety, and depression are comorbid with dementia and dementia caregivers suffer from these diseases (Ferrara et al., 2008; Fiske et al., 2009; Kuring et al., 2018; Kwak et al.,

2017; Mortamais et al., 2018; Muliya & Varghese, 2010) that can be treated with either pharmacological or psychological/psychosocial interventions (Bandelow et al., 2017; Ng et al., 2017; Worthen & Cash, 2020). However, in order to curb the further spread of the COVID-19 disease, it is important to maintain social distancing and follow the required public healthcare measures that are put in place (Wang et al., 2020). Consequently, for dementia caregivers to continue accessing the therapy that they need during the COVID-19 crisis, accessing psychological and psychosocial interventions such as Internet-based method is key to helping them remain safe (Cuffaro et al., 2020).

Aims and Objectives

The aim of this research proposal is to conduct a qualitative investigation to determine whether receiving Internet-based interventions is effective for professional dementia caregivers who are prevented by the COVID-19 pandemic from attending the traditional face-to-face therapy. The objectives of this research proposal are to answer some relevant questions to the accessibility of Internet-based interventions for professional dementia caregivers and to evaluate the effectiveness of these interventions.

Rationale/Justification

In the unprecedented time such as the coronavirus (COVID-19) pandemic, it is necessary to determine effective ways to deliver therapy to professional dementia caregivers who require receiving psychological or psychosocial interventions. The unprecedented coronavirus pandemic has forced people to go into isolation (Wang et al., 2020). With the fear of new outbreaks of the virus, meaning that there is going to be longer periods of isolation for people with dementia and their caregivers if there is a renewed lockdown (The Guardian, 2020; Wang et al., 2020). Continued and prolonged isolation have significant negative consequences not only on the wellbeing of people with dementia but also on that of their caregivers (Gerritsen & Oude Voshaar, 2020; Wang et al., 2020).

Literature Review

Numerous studies conducted in the recent years have reported that informal/family dementia caregivers can access Internet-based interventions, and they received positive effects on their wellbeing (Boots et al., 2014; Cristancho-Lacroix et al., 2015; Egan et al., 2018; Guay et al., 2017; Hurley et al., 2014; Jensen et al., 2015; Stefanopoulou et al., 2019; Zhao et al., 2019). Furthermore, Aledeh and Adam (2020) conducted a literature review

evaluating the efficacy of those interventions for dementia caregivers including both professional and informal ones. The review reported that while there was a great amount of evidence for informal dementia caregivers, whether Internet-based/Web-based interventions were effective for professional dementia caregivers' wellbeing or not remained to be explored. (Aledeh & Adam, 2020). These findings suggest that there is the need to further research into these technological interventions. Considering the challenging wellbeing status of professional dementia caregivers, it is important to determine helpful approaches to deliver the required psychological and psychosocial interventions for professional dementia caregivers.

Research Question

The following research questions will be developed and addressed: (1.) how accessible is internet-based intervention for professional dementia caregivers? And (2.) how effective is internet-based intervention for professional dementia caregivers?

Method

Study Design

This study will adopt a qualitative research design using thematic analysis in order to capture participants' experience and their subjective meanings as it will

allow researchers “to gather detailed and specific information” (Booth et al., 2016; Clarke & Braun, 2018). The interview will be on Internet-based interventions and a focus group with semi-structured interviews (Green & Kotera, 2020). Furthermore, specific variables and data that are associated with the study will be analysed (Denscombe, 2017).

Study Setting

In the organisation that we intend to recruit study participants, there are eight hospitals and nine long-term (nursing homes) care facilities with each of them having more than a couple of dementia ward including geriatric psychiatric wards (Stadt Wien, 2020). Five dementia wards will be selected for the recruitment of study participants. The interview will allow minimal intrusion in order to help participants feel at ease as that would make them more open to discuss freely (Edwards & Kotera, 2020).

Reaching Out to The Right Population

Sampling and Recruitment

Choosing the right populations is a crucial aspect of any successful research project (Kendall, 2003). Participants to be recruited for this study will be professional dementia caregivers caring for people living with dementia. The participants will be drawn from carers in institutional facilities

such as nursing homes or residential homes, and community care settings. We plan to recruit the proposed study participants by sending _____ through psychologists/psychotherapists who deliver Internet-based interventions to this caregivers’ population. Additionally, in order to capture participants' experiences brief telephone or email interviews will also be used. The sample size, that is the minimum number of participants for the study sample will be calculated in order to allow us to detect any clinically important difference between groups being compared (Kendall, 2003).

Eligibility Criteria

For participants to be eligible for the study, they must be 18 years old and above, and must be caregivers working with people living with dementia. Their workplace should either be in a nursing home or care facility, geriatric psychiatric department, day care centre and or in the community care setting: within the walls of care recipients' homes. These caregivers will also be receiving any form of psychological or psychosocial intervention.

Inclusion criteria

To be included in the study, carers must be caregivers of people with dementia either in a nursing facility, and community care setting. The caregivers can be either

professionals on paid services or those in voluntary service.

Exclusion criteria

Caregivers not caring for people living with dementia will be excluded from the study. Also, caregivers with cognitive decline will not be included in the study.

Informed Consent

Each of the participants will be given a consent form to fill in ensuring them that their data will be kept safe and used ethically until they are safely deleted.

Demographic Outcomes

Demographic data from all participants which include their age, gender, marital status, ethnicity, level of education, and the number of years working with people with dementia will be collected (Edwards & Kotera, 2020).

Data Collection and Analysis

Data for the study will be collected through interviews and will be analysed. Because we will be applying the qualitative method, the data collection through sampling will either take the semi-structured form (Creswell & Creswell, 2018). Data will be analysed by co-authors, and triangulation will be formed with another researcher in the field to ensure that data analysis was done fairly.

Procedure

There will be information available for the participants to know what the study is about and forms to seek participants' (Informed consent) consents. The interview questions will be open-ended in order to allow the participants the freedom to express themselves well (Gaudet & Robert, 2018). The audio recordings which will be transcribed and coded (Denscombe, 2017). Participants can withdraw from the study at any time they feel to do so without any consequences as regards their interventions.

Ethical Considerations

Ethical approval of the study will be sought from the university and care facility's review board. The data collected will be treated complying with the Data Protection Act 1988. Consequently, participants' personal data will strictly be protected as regulated by the general data protection regulation (GDPR) (Mourby et al., 2019). The research study will be in accordance with the Helsinki Declaration of 1975 (Edwards & Kotera, 2020).

Remuneration

None of the proposed participants will be rewarded nor be given any incentive for participating in the study.

Data Protection

All participants will be assured that their privacy will be ensured. The information collected from them as part of the study will be securely stored and only accessible by (research team) us and any future collaborators. In order to ensure anonymity, a unique participation number will be assigned to each participant. There will be no mention of names or places to ensure participants' confidentiality.

Study Strengths and Limitations

This research applying qualitative research approach will enable us to capture participants experience (Adu, 2019; Booth et al., 2016; Creswell & Creswell, 2018). It is hoped that this study will provide some insights into how professional dementia caregivers can benefit from internet-based psychological interventions on their wellbeing and care burden, by identifying the strengths and weaknesses of this approach.

Limitations

The relatively small participants' population size will make it difficult for the outcome or findings of this research to be generalisable (O'Cathain et al., 2013). Furthermore, research show that not all qualitative research undertaken with trials are published in peer-review journals (O'Cathain et al., 2013).

Knowledge Gaps

From the literature review carried out there are a few gaps in knowledge that exist regarding factors that influenced informal/family dementia caregivers' mental wellbeing but to date not much has been researched into these interventions with professional dementia caregivers. Therefore, this study will enable us to answer some of the research questions whether professional dementia caregivers are more mentally resilient than informal/family dementia caregivers. Additionally, this study will enable us to understand the contributing factors that are responsible for the outcome.

Outcomes and Dissemination

This research will be disseminated by pitching findings of the study to stakeholders, policymakers, researchers and non-researchers through conferences, peer-reviewed journal publication and through the media. Furthermore, findings and highlights about the research findings will be published using the social media such as Twitter, LinkedIn and ResearchGate.

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