PSYCHOLOGICAL OUTCOMES OF TELECARE USE FOR WORKING FAMILY CARERS OF OLDER PEOPLE

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ABSTRACT: Informal carers face constant pressure due to the increasing need for long-term care for older people. While society expects informal carers to keep providing care, existing supportive measures only partly respond to their needs. Telecare has the potential to solve some of their challenges. The present study aims to identify the positive and negative psychological outcomes for working family carers of older people of using six features of telecare services. We conducted an intervention study on a purposive sample using a quasi-experimental research design. The study was performed in 2018–2019 in the Central Slovenian region. Two telecare services were tested for four months by 22 working family carers of older people. The data were collected through semi-structured interviews; each of the participants was interviewed in the first month of testing and at the end of the intervention study. The interview transcripts were subjected to thematic analysis. Activity monitoring and app notifications were identified as the features with the most outcomes. The most commonly mentioned positive psychological outcome of telecare for family carers was reassurance, followed by peace of mind and reduced anxiety. The most frequently mentioned negative outcomes were anxiety, distrust and stress.

1 INTRODUCTION

Slovenia is one of the most rapidly ageing European countries [1] where informal care remains the most important form of long-term care (LTC) for older people [2]–[4]. At present, support for informal carers, who are the backbone of Slovenian LTC, is scarce, although the Active Ageing Strategy [5] recognizes the importance of improving “support for informal carers and their integration into the system of LTC” [5, p. 48]. According to the European Quality of Life Survey (2016), 15% of the Slovenian population (18+) provide informal care at least once a week [6]. The results of the SHARE survey indicate that in 2013, 75.5% of people aged 65+ who received some form of care at home received only informal care, 6.7% received only formal care and 17.8% received a combination of the two [7], [8].

The first phase of the ongoing study “Evaluating pilot projects in the field of long-term care in Slovenia” [9], conducted in three Slovenian pilot regions in 2019, provided a more detailed insight into the characteristics of informal carers of older people (n = 197). Almost two out of three (65.5%) carers were female, 50.8% were caring for their parents, 35.5% for their partner and 9.6% for another relative. Moreover, 68.6% lived in the same house as the person they cared for and 11.3% within walking distance. They provided informal care and assistance for an average of 43.2 hours a week (SD = 48.70), and 34.7% of them reported feeling quite burdened or very burdened (14.2%). Almost a third (30.4%) of them often, and 10.5 % always, experienced stress due to constantly having to coordinate a job, family and care. In addition, 28.3% of informal carers often, and 14.7% almost always, lacked time for themselves due to their caring duties. Furthermore, a third of them sometimes, and 23.7% quite often or almost always, felt that they would soon no longer be able to care for the older person.

While society expects informal carers to keep providing care, existing supportive measures only partly cover their needs [2]. Currently, many informal carers struggle to combine work and care, and telecare [10]–[13], can play a significant role in this regard [14]. While several studies have focused on outcomes of telecare use among older people [15]–[17], understanding of the psychological outcomes of telecare use for informal carers is limited [18]–[22]. A recent scoping study identified six psychological outcomes of telecare use for informal carers: peace of mind, reassurance, anxiety, depression, stress and feeling burdened [22]. However, it did not address how the specific technological features of telecare might contribute to the positive or negative psychological outcomes. To fill this gap, the present study aims to identify potential positive and negative psychological outcomes of telecare use for working family carers of older people and to review their relationship with the functionalities of various telecare services.

2 METHODS

2.1 STUDY DESIGN AND PROCEDURE

We conducted a four-month intervention study using a qualitative research design [23]. The qualitative methodology played a fundamental role in this study, while the quantitative methodology was used only for the purposes of capturing objectively measured facts and socio-demographic characteristics. The intervention was performed in 2018–2019 in the Central Slovenia region. A total of 26 dyads, including older care receivers and their primary family carers, were recruited. In accordance with the aim of the study, surveys and interviews were conducted with working family carers only. Basic social, health, care provision and demographic data were collected through the survey at the beginning of the intervention. Subsequently, two semi-structured interviews per family carer (at the first and fourth month) were conducted, each lasting approximately one hour. They were asked about their caregiving situation, their experiences with new technology, their use of the tested telecare services and the psychological outcomes of telecare. In-depth interviews were audio-recorded and fully transcribed. Personal information was anonymized. All participants received gift certificates in appreciation of their time. The study was approved by the Slovenian Commission for Medical Ethics (0120-193/2018/15).

2.2 APPARATUS

Older people, as the care receivers, had one of the two sets of tested telecare equipment installed in their home, while their family carers used the telecare mobile app which enabled them to monitor certain activities in the older person’s home and to receive notifications. Both tested services had motion and door sensors, an emergency pendant, a smoke detector and a mobile app for carers, with alarms in the form of push notifications and activity monitoring.

In addition, the second service, used by 7 out of 22 carers, offered a 24/7 call centre and a fall detection feature. Participants were not charged for the use of the equipment or service.

2.3 PARTICIPANTS

Due to the restrictive eligibility criteria, purposive sampling was used to identify and select care receivers and their family carers. The eligibility criteria for family carers were that they should be (i) a primary carer; (ii) a family member of an older person; (iii) a provider of LTC to an older person; (iv) an owner of a smartphone; and (v) interested in study participation. Care receiver's eligibility criteria were that they should (i) be interested in study participation; (ii) be aged 65+; (iii) need help with activities of daily living; and (iv) live alone in their own household. Of the 26 dyads of care receivers and carers, 22 completed the study. Carers ranged in age from 35 to 67 years (M = 53.9, SD = 7.56). Most of them were female (n = 14). On average, they provided 8.5 hours of care per week (SD = 12.15) and had been doing so for an average of 5.9 years (SD = 5.87). The majority of carers were care receiver's children (n = 20), and two were daughters-in-law. Care receivers were on average 83 years old (SD = 6.04), ranging from 73 to 92 years. All but two were females, and all but one had fallen in the last five years, 14 of whom required medical assistance afterwards. Five of them were severely dependent, eight moderately dependent and nine slightly dependent.

2.4 ANALYSIS

A descriptive analysis of the quantitative data was conducted. The semi-structed interviews resulted in 755 pages of transcribed interview records. The qualitative data were subjected to thematic analysis using Atlas.ti 8 software. Structural coding was used. This is question-based code that "acts as a labelling and indexing device, allowing researchers to quickly access data likely to be relevant to a particular analysis from larger data set" [25, p. 141], [26, p. 84]. Deductive and inductive approaches were combined for data coding and analysis.

3 RESULTS AND DISCUSSION

Six telecare features were considered: sensor-based motion detection on the app (SA), notifications and alarms on the app (NA), a wearable emergency pendant (EP), a smoke detector (SDT), call centre assistance (CC) and a fall detector (FD). Activity monitoring and app notifications were identified as the features with the most outcomes. The most frequently reported positive psychological outcome was reassurance (n = 44), followed by peace of mind (n = 31) and reduced anxiety (n = 25). In addition, family carers mentioned several other positive psychological outcomes of telecare use, including an increased sense of control (n = 14), reduced stress (n = 11), feeling less burdened (n = 10), positive feelings (e.g. happiness, joy) (n = 4), a sense of relief (n = 3) and satisfaction (n = 2). These findings support those of previous studies [19], [20], [22], [27]–[29]. They also contribute to new knowledge by demonstrating that reassurance is the most common positive psychological outcome before peace of mind and other outcomes. Reassurance was mostly related to SA, which enabled carers to remotely monitor the activities of an older person, e.g. to verify that (s)he has come home safely and is moving and is, therefore, well and safe. Family carers mentioned that they found it easier to go on a business or a private trip because they would be notified with "live alerts" if something was wrong (NA). They felt supported knowing that a need for urgent care would be noticed quickly (NA, CC, EP). This reassurance made the carers' work easier and improved their concentration and focus at work. Peace of mind was most frequently related to having a safety net and thus feeling that they were not alone in their situation (CC, SDT, EP), an older person's safety (NA, CC), and a rapid reaction in case of emergency (NA, EP, CC). Knowing that an older person was well (SA, NA) and that (s)he could call for help in an urgent situation (EP) reduced the carers' anxiety. For example, being able to rely on SA reduced their anxiety when they were away or busy and thus not being able to visit frequently, when negative thoughts about the older person's situation arose, when the older person did not answer their phone calls, or when the older person had an appointment outside the house and the carer could confirm whether (s)he had returned safely.

The most frequently mentioned negative outcome was anxiety (n = 10), followed by distrust (n = 5), stress (n = 4), lack of relief (n = 3), feeling burdened (n = 3), feeling uncomfortable (n = 2) and being in doubt (n = 2). Reduced peace of mind, a sense of guilt, feeling a moral obligation, a false sense of security, feeling bothered or feeling the solution had added to their problems were mentioned only once. Many of the negative psychological outcomes mentioned were the result of false alarms or equipment malfunctioning. However, some carers pointed out that the emergency pendant did not bring them any relief because the older person did not want to wear it. In addition, one carer reported that the older person was still active and thus going out on her own, so he felt that his burden remained unchanged (SA). Another carer had doubts that the older person would be able to press the emergency pendant if something happened (EP). Another carer felt uneasy and worried when she received a valid alarm (NA), and one also mentioned that she frequently analysed the movements of the older person in the apartment (SA) and became worried about some of the old person's daily patterns, which was similar to the findings of Groeneveld et al. [30]. In addition, one carer felt like she was stalking the older person and invading her privacy (SA). Similar privacy concerns were raised in other studies [31], [32]. One carer also felt that checking up on older person was additional work for her (SA). Another carer saw that her mother-in-law was alone and reported feeling guilty for not visiting or calling enough (SA). Negative psychological outcomes such as feelings of false security and being bothered and distressed by false alarms have also been revealed in prior research [18], [28], [33]. In the present study, all call center users mentioned positive psychological outcomes in relation to it. They mostly felt reassured by their service. However, a few participants (n = 5) who did not have access to the call centre service felt reluctant to the idea of using it, saying that they might not have enough information about the older person to react well, that they would not feel comfortable talking to a "stranger" and that their situation was too specific for a call centre to be helpful. Such results are not aligned with the findings from an earlier Slovenian study [34], in which a care assistance centre was perceived as the most important added value of a telecare system.

The present study confirmed previous findings regarding many positive outcomes of telecare for working family carers [22]. The few negative psychological outcomes in our study were mostly triggered by technical failures and false alarms, although some participants were less disturbed by them than others (see also [35]). In sum, this study confirms the complex relationships between the functionalities of telecare services and psychological outcomes for working family carers. These relationships, in combination with other care provision factors such as geographical distance, warrant further empirical and conceptual research.

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