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INTERVENTIONS TO PROMOTE CAREGIVER RESILIENCE

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Abstract

Purpose of review—Family caregivers of patients with cancer often spend a great deal of effort on physically and emotionally demanding work while taking care of patients. However, the majority of caregivers are not properly equipped for their role as caregivers, which may lead to increased distress in both caregivers and patients. Herein, we reviewed the recent literature (last three years) examining online interventions that seek to support caregiver resilience and decrease distress.

Recent findings—Our search identified interventions involving three main themes: informational support, positive activities, and social support. These are mostly in the form of web-based tools and mobile apps targeting both usability and quality of life (QOL). Social network services (SNS) is also considered in this review as a new environment for caregivers to connect with other individuals with lived experience in similar circumstances.

Summary—Existing studies on online interventions to support caregivers is still at a formative development stage and pilot tests of feasibility, rather than a substantive body of randomized controlled trials to assess the impact in different user populations, or to determine specific factors that impact caregiver distress level or resilience. More research is needed to further assess the long-term effects of online interventions on caregiver stress and resilience. Also, the role of different types of social network services and new forms of interaction, such as conversational agents, has not yet been fully investigated in caregiver populations. Future research should strive to seek new modes of providing services that may present novel opportunities to enhance caregiver resilience and reduce distress.

Keywords

Family caregiver; cancer; mHealth; online interventions; stress; wellbeing

INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), cancer is the second leading cause of death in the US. However, the rate of cancer-related death has dropped by

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Conflicts of interest

None

26% in the last 30 years (1). With this continuous increase in cancer survival, there is a concomitant rising number of caregivers who provide long-term care for their loved ones who live with cancer and ongoing treatment or survivorship.

Family caregivers are the individuals who provide care for their family or friends, typically unpaid, in domestic settings (2). These caregivers often spend a great deal of time and effort on both physically and emotionally demanding work, such as forming treatment regimens, managing medications, coordinating regular clinic visits, and engaging with healthcare providers in clinical conversations (3,4). These significant demands result in a range of problems for caregivers, including financial issues (5), social isolation (6), poor sleep patterns and depression (7,8). These negative effects can last for a long period of time, even well after the patient's death (9,10).

Despite such physical, practical and emotional demands on their lives and time, caregivers of patients with cancer are expected to adjust to these changes. However, a majority of family caregivers report inadequate support in providing long-term patient care. They are often viewed as the 'invisible' workforce that provides care for the patients, and their roles are often hidden and under-recognized within the healthcare system (11*). Because most caregivers are not sufficiently equipped with skills and information to provide care for their patients, they often suffer from symptoms of depression and anxiety, which impacts their ability to concentrate (12,13) and therefore function optimally. Furthermore, caregiver symptoms have been found to concurrently impact patient clinical and mental health outcomes, given the heavy reliance on caregivers for managing patient symptoms and providing support (14). As a result, there is an increasing demand for understanding and meeting caregivers' needs through the application of caregiver-focused tools or instruments that provide information and support for a wide range of problems including psychological (15).

Technology-mediated interventions, including telemedicine, mHealth, and social media applications, have become commonplace in and accepted by the healthcare environment (16**, 18). Recent studies have highlighted the benefits of using online interventions to support caregiver resilience and assist in managing caregiver stress (15,17*). Over 35% of the population has access to a smartphone, and Statista anticipates the smartphone adoption rate to increase to 40% worldwide by 2021 (19). A recent survey of 112 caregivers indicated that most caregivers have high access to technology and the Internet (20). The younger caregivers (aged 18–64) stated that they expect more benefits from technology-mediated tools, and caregivers older than 65 years also believed that such technologies would help reduce their caregiving burdens. Recent systematic reviews on technology-mediated interventions designed for supporting family caregivers reported improvements in their targeted caregiving practice areas even though many interventions were still in exploratory phases (16). Studies highlight the need for targeted research hypotheses, although effectiveness for specific interventions and measures has been demonstrated (21**,22**), for example, self-compassion and mindful awareness have been shown to enhance caregiver coping (23).

Online interventions enable caregivers to easily access useful resources and participate in a variety of simple activities using their personal devices, such as smartphones or tablets. These interventions can serve as information resources (24,25*), enable access to healthcare teams (26), and provide an outlet for emotional ventilation through peer-to-peer interactions in various health contexts, including dementia, diabetes, and health failure (27,28). With online health interventions designed to provide support, regardless of time and place, caregivers can access such services with relatively less time and effort than traditional interventions.

Although the benefits of technology and the ways to effectively disseminate online interventions to caregivers is accepted by the healthcare system, only a limited number of evidence-based interventions are available. This gap is even more pronounced in long-term follow-up cancer care or survivorship settings. Previously conducted studies largely focused on the supportive needs of caregivers in the context of home palliative care or end-of-life care (9) rather than caregivers in long-term follow-up cancer care or survivorship. Therefore, the field has a limited understanding of the current status of online interventions designed to alleviate psychological burden and distress for many cancer caregivers, particularly across the trajectory of care, including into survivorship.

Herein, we reviewed the current status of online interventions designed to support informal/family caregivers during long-term cancer treatment and survivorship. By synthesizing the most recent and relevant studies, this review identified trends in the field and suggested future opportunities for supporting cancer caregivers with enhanced coping, resilience, psychological wellness, information, reduced distress, and social support.

METHODS

The purpose of this study was to review the most recent articles on online interventions that aim to alleviate informal/family caregiver distress and support their resilience. We searched for articles archived under PubMed, PsycINFO, and Google Scholar using various combinations of the following search terms: family/informal/caregiver, cancer/oncology, mHealth/online/internet/technology/digital health, and resilience/depression/distress/stress. Additional articles were also identified from the recent systematic reviews on technology-mediated interventions that aim to support caregivers. The current study was not aimed at providing a systematic review of the topic. Our search aimed to offer an overview of the most relevant literature on caregiver supporting intervention in cancer context and was limited to studies that explicitly mentioned caregiver's stress and resilience support as their main study goal and were published within last three years. We acknowledge that the search was not exhaustive, and there may be other articles that were not included in our review.

RESULTS

Search Results and Data Analysis

In the following sections, we provide an overview of the state of the current caregiving studies to improve resilience and alleviate stress. The authors regularly discussed included studies to understand consistent themes and group them into overarching categories. We

categorized the identified articles into three main themes: (1) knowledge and information; (2) positive psychological activities; and (3) social support. Please see Table 1 for the summary of current online interventions for caregivers of cancer patients.

Knowledge and Information: Support Caregivers with Resources

Caregivers are often faced with an overwhelming amount of clinical information and rely heavily on healthcare providers to help them understand complex information (29). Information delivery and resource sharing through online interventions, such as home video conferencing, web-based tools, and mobile apps are considered as beneficial as in-person interactions with healthcare providers.

For example, videoconference technology has been used to alleviate the emotional burden in caregivers. Blackstone et al. conducted a randomized controlled trial with 332 patient-distance caregiver dyads in 32 outpatient cancer centers to understand the effectiveness of a video conferencing intervention on caregiver and patient's distress, anxiety, depression, burden, self-efficacy, and emotional support (25*). The study particularly addressed the barriers of distance caregivers who live one hour apart from patients. The video conference intervention was designed to provide participants with four personalized coaching sessions via videoconference. Resources provided during the coaching sessions included information support, such as useful communication strategies with close others and self-care techniques. Outcome variables were measured at baseline, four months, and six months. The study is currently ongoing; the intervention has received positive feedback from participants and clinicians. However, situational details that caregivers may encounter (e.g., waiting time at the clinic, technology literacy, quality of wireless connections) were pointed out as future considerations that must be addressed to draw successful adoption of the intervention.

Also, a randomized-controlled trial with a qualitative interview component investigated the effectiveness of an intervention designed to support quality-of-life (QOL) of male spouses of female breast cancer patients (30*). Participants assigned to the treatment group were able to access the web-based Male Transition Toolkit (MaTT) intervention for four-weeks. Six specific themes were addressed, including common changes to expect, important health information, and other resources. Generally, participants in the intervention group found MaTT to be helpful in reducing their distress and also easy-to-use. Even though caregiver's QOL scores were not significantly decreased, the intervention was perceived to be acceptable and feasible with ease-of-use. The study pointed out that the frequency and duration of engagement with the intervention should be further investigated.

Similarly, the Oncology Family App was designed to support the caregivers of cancer patients (26**). The app provided useful phone numbers, links to the maps for statewide hospitals, and emergency contacts in an easy-to-access manner. The app also provided access to patients and families for reviewing lab test results to understand their current situations. In an iterative user-centered approach, caregivers, patients, and clinicians were involved in the development process. Further studies will be conducted to measure short- and long-term effects of the app in the treatment process and caregiver and patients' perceptions.

Positive Psychological Activities: Promoting Caregiver Well-being

Participating in an in-person class is often challenging for patients with cancer and their caregivers, due to time constraints and other restrictions. To alleviate these issues, recent studies provide online-based simple activities, such as meditation, through mobile apps and websites. Simply engaging in these activities has been shown to generate a positive mindset and confidence for individuals about their ability to cope with a challenging situation and manage negative feelings (31,32).

Kubo et al. investigated the effectiveness of an online-based/mobile app that provided meditation guidelines for caregivers and patients who were undergoing chemotherapy (33**). Participants were asked to engage in the daily basis program for 10–20 minutes throughout the 8-week study period. To enhance understanding, short (1–2 minute) information videos were provided every few days. Participants' distress, anxiety and depression, sleep quality, fatigue, and mental and physical domains of HRQOL were measured. Nine caregivers also completed the post-intervention phone interview. Although there were no significant changes in anxiety, sleep quality, and mental health (specific domain of HRQOL measure), caregivers reported decreased stress, depression, and fatigue, and improved physical health (specific domain of HRQOL measure). Overall, the results showed that the mindfulness intervention was effective and well-used by participants.

Another study applied user-centered approaches in developing a psychosocial intervention for parents of children with cancer (34**). Web-based Electronic Surviving Cancer Competently Intervention Program (eSCCIP) was designed to alleviate anxiety and posttraumatic stress syndrome (PTSS) for caregivers. Video materials and interactive contents focused on four modules, including cognitive-behavioral skills, the story of other families undergoing similar situations, and activities to enhance mental wellness. As the study included the participatory design sessions with the limited number of participants, a further usability test with larger sample size will be needed for future investigation to confirm the initial positive findings.

Chaar et al. recently suggested smartphone-based mHealth interventions (Roadmap 2.0) to promote positive activities for family caregivers in the context of hematopoietic stem cell transplant (HCT) (35**). In this study, 24 caregivers of patients undergoing first-time HCT participated in home interviews. Caregivers shared effective stress relieving strategies, perceived benefits of simple positive psychological activities, such as Pleasant Activity Scheduling, Gratitude Journaling, Savoring, Random Acts of Kindness, Positive Piggy Bank, and Signature Strengths, that could be applied to the mobile app. The study results highlighted caregivers' strong desire for engaging in positive activities to reduce stress and enhance their mental and physical well-being. Roadmap 2.0 is currently being developed and will be tested in a randomized controlled trial in family caregivers of HCT patients.

Social Support: Ventilating Feelings and Acquiring Coping Strategies

As smartphone and social media use are permeating individuals' lives, online peer support groups have become useful resources for exchanging ideas among people who undergo similar situations. In many chronic conditions, caregivers take advantage of exchanging

useful health information and share experiences with other peers (37,38). Such opportunities to interact with individuals in similar circumstances enables caregivers to gain from indirect experiences and obtain useful resources, resulting in improved stress-coping strategies and resilience (36).

Wang et al. conducted a quasi-experimental pre and post-study in parents of patients with Acute lymphoblastic leukemia (ALL) to understand the effectiveness of a smartphone-based intervention (Care Assistant) and social network services (WeChat) on caregiver status, including social support, anxiety, depression, care burden uncertainty in illness, quality of life, and etc. (39*). Eight different themes were embedded in the app (Personal Information, Treatment Tracking, Family Care, Financial and Social Assistance, Knowledge Center, Self-Assessment Questionnaires, Interactive Platform, and Reminders) and the social network site provided updated information and interaction with clinicians. 49 and 43 parents in intervention group and control group completed the study respectively. After the 3-month intervention, parents reported decreased anxiety, depression, uncertainty, and knowledge needs. Also, the knowledge of parents had significantly enhanced. However, in the observation group, care burden and knowledge were significantly increased, whereas uncertainty in illness significantly decreased over the course of three months.

Fallon et al. conducted an online survey with the members of the American Cancer Society's Cancer Survivors Network (CSN) to understand their usage of the site (40*). The survey results showed that both patients and caregivers desire informational and emotional support from other similar situations in the cancer context. This result highlights the role of social support, especially in rare cancer populations. As users can access CSN for free, this online social networking site has potentially great benefit for users worldwide.

DISCUSSION

Formative or/and Summative Evaluation of Interventions

While caregiver support interventions developed in the past focused mainly on information delivery and needs of engaging caregivers in the conversation with providers, studies in the last three years have begun introducing other foci, including the effectiveness of positive activities and benefits of having social supports through social network services. However, the outcome measures of the studies we reviewed were largely formative and/or summative evaluations of interventions, which means that the actual effectiveness of the intervention was not yet tested in a rigorous manner (e.g., prospective, multi-center, randomized controlled design). As evaluation phases should be considered as important in the development of an intervention, studies should consider active adoption of interventions in the healthcare environment. Future studies would benefit from large-scale usability studies, along with design of rigorous implementation and dissemination strategies.

The Needs of New Modes of Interactions

Our review revealed that there was a limited mode of interaction implemented in the current healthcare system. The studies herein focused primarily on web-based interventions or smartphone-based technology. Given the current social media environment, there are rich

opportunities through different social network services, or newer technologies, such as conversational agents and healthcare robots, that should be actively considered for further study. A recent systematic review conducted by Laranjo et al. indicated that conversational agents can be effective solutions in a number of different health contexts (41**). The article pointed out that conversational agents (e.g., Amazon Alexa, Google assistants, Siri) have potential for great benefit in healthcare by assisting providers and providing around-the-clock support for patients and caregivers in the home environment. Similarly, Wang and colleagues suggested positive consequences of having social robots in the context of dementia care (42). By conducting semi-structured interview and a simple collaborative task between a patient and the robot, the study suggested future possibilities of alleviating caregiver's burden via robots. However, most of the recent studies were conducted in lab settings, rather than within the actual environment where caregiver supporting tools are intended for use. New assistive technologies still need further investigations to be implemented in patient and caregiver's home settings.

CONCLUSION

Online interventions provide rich opportunities for improving resilience and effective stress management skills in the context of chronic medical conditions, including among caregivers of cancer patients. By adopting interventions through smartphone or laptop platforms, caregivers have the potential to access useful information, perform simple and easy stress relieving activities, and engage in conversations with peers who undergo similar circumstances. Multidisciplinary collaboration and incorporation of usability testing in the design of these technology-mediated interventions are critical in the evaluation of newer technology. Future studies should explore whether new technologies that seamlessly and naturally integrate into caregivers' lives may be novel strategies to support cancer caregivers.

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KEY POINTS

- The majority of family caregivers of cancer patients are inadequately equipped with skills and information to provide care for their patients, resulting in caregiver distress.
- Online interventions enable caregivers to access useful resources, such as health information, peer support groups, and guidance for simple stress relieving activities using personal devices.
- Although the field involves ongoing discussions about the benefits of technology in supporting caregiving practices and ways to effectively disseminate them in the current healthcare environment, a limited number of evidence-based interventions are available in long-term follow-up cancer care or in survivorship settings.
- Previous interventions that provide informational support, guidance for positive activities and opportunities for social support are heavily focused on formative and/or summative evaluations of interventions.
- As recent technologies (e.g., conversational agents) increasingly show benefit in the healthcare environment, it remains important to investigate characteristics of such interactive technologies for supporting caregivers in home settings as well.

Table 1.

Summary of current online interventions for caregivers of cancer patients

Reference	Authors (Date)	Population	Sample Size	Study Design	Types of Interventions	Major Outcome Variables (Caregiver)
[25]	Blackstone et al. (2019)	Distance caregivers at outpatient ambulatory clinics	332 patients -caregiver dyads	Randomized controlled trial	Personalized coaching sessions via videoconference	Caregiver's distress, anxiety, depression, burden, self-efficacy, and emotional support
[34]	Canter et al. (2019)	Caregivers of cancer patients	17 caregivers (phase1)/5 caregivers, (phase3)/4 caregivers (phase4)	Four phased participatory process; (a) creating the multifamily video discussion group (MFVDG) and other video contents, (b) developing the initial prototype, (c) Think Aloud testing, and (d) beta testing	Interactive website	Acceptability, feasibility, usability of the intervention, and website usage data
[35]	Chaar et al. (2019)	Caregivers of patients undergoing hematopoietic stem cell transplant (HCT)	24 caregivers	Semi-structured interview	Mobile app	Experiences of being a caregiver, effective stress relieving strategies, and perceived benefits of simple positive psychological activities
[40]	Fallon et al. (2018)	Caregivers and patients engaged in American Cancer Society's Cancer Survivors Network (CSN)	4,762 caregivers and patients with cancer	Online opt-in self-report survey	Online social networking community	CSN use and perceived value of features, health, health behavior, and cancer experiences
[33]	Kubo et al. (2019)	Cancer patients who received chemotherapy and their caregivers	97 patients undergone chemotherapy and 31 caregivers	Randomized controlled trial	Mobile/online (mHealth) intervention	Retention rate, adherence, participant-reported measures, distress, anxiety and depression, pain, sleep quality, quality of life, fatigue, posttraumatic growth, mindfulness, and post-intervention interview
[21]	Marzorati et al. (2018)	Caregivers of adult cancer patients	24 studies that include a technology-mediated intervention for caregivers of adult cancer patients	Systematic review	Telehealth interventions (web-based platforms and telephone calls)	N/A
[22]	Ploeg et al. (2018)	Caregivers of patients with chronic conditions	14 studies on web-based interventions, compared with no or minimal Web-based interventions, on caregiver outcomes	Systematic review and Meta-analysis	Web-based platforms	N/A
[16]	Shin et al. (2018)	Caregivers of patients with cancer	18 studies published on the support of cancer caregivers with health technology	Literature review	Mobile interventions and web-based platforms	N/A
[26]	Slater et al. (2018)	Families of patients with cancer	9 staff and 6 caregivers in oncology settings	Interview, analyzed download metrics	Mobile app	Feasibility, and usability of the intervention

Reference	Authors (Date)	Population	Sample Size	Study Design	Types of Interventions	Major Outcome Variables (Caregiver)
[30]	Struthers-Montford et al. (2017)	Male spouse of patients with breast cancer	40 women with breast cancer - spouse dyads	Randomized controlled trial, mixed methods, concurrent feasibility study	Web-based platform	General self-efficacy, caregiver guilt, quality of life, and feasibility
[39]	Wang et al. (2018)	Parents of children with acute lymphoblastic leukemia	101 caregivers	Quasi-experimental pre- and post- design study	Mobile app	Anxiety, depressive disorder, perceived social support, burden of care, parents' perception of uncertainty in illness, quality of life, and parents' existing knowledge and knowledge needs