

Review Article

The Effectiveness of Social Media Support for Caregivers: A Systematic Review

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Abstract: Background: Caring for patients living with long term conditions is a long-term task. The augmenting use of social media (SM) supports for health information and communication has created new opportunities for new models of health-care. Objectives: This study aimed to explore the effectiveness of SM support for caregivers. Methods: This systematic review mainly includes research over the past decade on caregivers for chronic diseases, with the results focusing on SM support for caregivers. Results: This literature review found that SM-based interventions can meet caregivers' needs and have a positive impact on caregiver burden (CB) of chronic diseases such as cancer, dementia and stroke. Experimental studies of health interventions for stroke caregivers (SCs) through WeChat interventions have been limited. Conclusion: More quantitative studies are needed in the future to explore the effectiveness of WeChat as an intervention in the burden of SCs.

Keywords: Social Media; Caregiver; Burden; WeChat

1. Introduction

According to the World Health Organization^[1], 41 million people die each year because of chronic diseases such as cardiovascular disease, cancer, diabetes, respiratory disease and mental illness. The number of people suffering from these chronic diseases is on the rise^[2]. As hospital care shifts to family or community care, patients increasingly rely on caregivers for support in their daily lives^[3]. Caring for people with chronic diseases is a long-term task. These long-term informal caregivers can be spouses, children, relatives, friends or neighbors of the patient, who provide care related to an underlying physical or mental disability, but the care is free^[4]. These informal caregivers undertake complex and difficult

tasks and consequently seek emotional support from people who understand their difficulties. In addition, they seek information about the prognosis or may knowledge about how and where to get support^[5]. Lack of coping methods or poor coping methods can damage the physical and mental health of caregivers, increase caring related injuries and even have a negative impact on patients^[6].

In recent years, many researchers have offered insights into the emerging use of SM in health-care. A systematic review from Han, Lee and Demiris (2018) found that the use of SM in cancer care would help improve communication and support between patients, caregivers and clinical practitioners and ultimately improve patient

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care^[7]. Similarly, a scoping review found the ability of SM to promote disease surveillance, health education, knowledge dissemination and collaboration among health providers in countries with not high incomes^[8]. However, misinformation or poor communication of information can lead to health behavior and adverse health consequences between users, as well as hysteria and confusion^[8]. Therefore, the impact and effectiveness of the use of SM interventions in health care on the behavior and health consequences of caregivers with chronic diseases is still worth exploring.

2. Background

Caregivers spend an average of about eight hours daily on caring, with much or less time for themselves^[9]. At the same time, caregivers lose their rest time and lack of sleep due to caring tasks^[10]. Additionally, the caregivers' quality of life was reduced due to the increase of caring tasks, which resulted in the loss of group activities such as attending parties and worship[11]. Some caregivers have suffered back muscle injuries while transporting patients, while others have become anxious about how to cope with daily caring for patients [9,10,12]. These experiences can place enormous stress on caregivers, which may limit their ability to use internal and external resources to deal with and cope with day-to-day problems^[13]. Caregivers may experience anxiety and depression due to the amount of time they spend on routine care and the way they pay for care, both of which are related to CB^[14]. Additionally, caregivers may also be burdened by patients' disabilities and cognitive abilities, as well as their own age, gender, and financial status^[15-17]. Moreover, caregivers feel a lack of skills and confidence to provide appropriate care, which may lead to increased patience-caregiver stress^[18]. On the contrary, the ability to adapt and solve problems creatively, to believe in self ability to cope with stress, and to keep in touch with others are all internal human forces that can enhance happiness^[19]. Hu et al. proposed that caregivers should be given appropriate home care guidance, social support and psychological counseling to reduce their caregiver burden^[14]. Thus, it is crucial to blossom acceptable, creative and cost-effective approaches to caring support for caregivers.

Recently, there has been a lot of interest in using web-based interventions to support caregivers. It

has been suggested that providing health care interventions over the Web might improve accessibility of services and reduce health care costs^[20]. With growing evidence of the positive role of the web in caregiver centered care, a review finds that web-based programs can improve the health or well-being of caregivers by intervening in the burden of care, depression, self-efficacy, and self-confidence^[21]. Whereas, another review shows that web-based interventions decrease in use over time of care and that interventions should be tailored to the caregivers' stage-specific needs for the patients' overall care trajectory^[22]. With the popularization of the Internet and new media, the emergence of SM has brought people a new way of communication, conversation and thinking^[23]. SM, is a transformation from a static "Web 1.0" platform to a "Web 2.0" platform. The one-way flow of information is transformed into user-centered generated content, usability, engagement culture and interoperable^[24]. SM mainly includes forums (e.g., Postbar, Yelp), social sharing services, such as YouTube, Instagram and social networking services such as Facebook, Skype, and Whats App, which is a series of online tools centered on social interaction^[25]. The augmenting use of SM for health information and communication has created new opportunities for new models of health-care^[26]. Caregivers, who are on the front lines of health, are using SM heavily for support^[27,28].

Like Facebook, the free WeChat app of Tencent, launched in 2011, has become the most popular and frequently used SM platform in China^[29]. WeChat offers a number of services for everyday life, including free phone calls, instant messaging, private groups, browsing and posting moments information sharing^[30]. WeChat is not only a mobile application installed on smart phones, but it has been integrated into most people daily lives^[29]. It is now an inevitable tool that is changing users' daily lives in many ways^[31]. Most importantly, through the different functions of WeChat, multifarious health information is continually come into being and disseminated among a large number of users, which provides great potential for the impact of WeChat on public health^[32-35]. However, caregivers have many tasks to complete every day and the information on SM is indiscriminate and unselective, so they do not have much time to use social platforms to obtain information^[36]. Our understanding of how SM-based interventions assess the needs and impact of caregivers is limited, so using SM to intervene on caregivers is worth exploring. The mainly purpose of this literature review was to assess interventions using SM based on CB and needs.

3. Search strategy

A literature review was searched in the following online database for relevant articles: MEDLINE, CI-NAHL, Academic Search Complete, APA Psyc Articles, Pub-Med, Health Source: Nursing/Academic Edition, using the following key concepts: "SM", "caregiver", "caregiver burden". These searches were proceeded using a set of synonyms and alterable structures for key concepts: "caregiver" or "family carers" or "family caregivers" or "caregivers" or "caregiver burden" or "caregiver burnout" or "caregiver stress" or "caregiver strain" or "caregiver fatigue", "SM" or "Facebook" or "Twitter" or "Instagram" or "Snapchat" or "Tumblr" or "WeChat" or "LinkedIn" or "My space" or "YouTube" or "Phorum" or "Yelp" or "Flickr", then crossed-matched

all above terms using "AND". A total of 657 articles published within the past 10 years during the years of 2010 and 2020. SM has become increasingly popular in the health care system in the last decade. After removing the repetitions and choosing the English only, there were 555 left. Through reviewing the titles, removing the study protocol, not focus on caregivers, not using SM and not full-text, after that choosing relevant articles related to chronic disease, like respiratory disease, cardio-vascular disease, diabetes, and cancer, then 60 articles reviewed by abstract, a final set of 15 articles were selected as being primarily relevant with this review, the Prisma flow diagram as shown in the **Figure 1.** Specifically, the goal of the review was to map a literature synthesis of SM-based health interventions for caregivers:

- 1) Caregiver needs
- 2) Caregiver usage of the SM interventions
- 3) The impact of SM interventions on caregivers
- 4) The benefits of using WeChat interventions

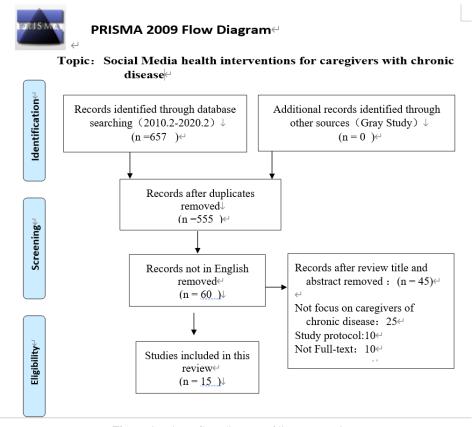


Figure 1. Prisma flow diagram of literature review.

4. Findings

4.1 Theme 1: Caregivers needs

New roles have changed the daily lives of caregivers. Caregiver, is a new role, because not only do they have to complete their daily work, but also to assume the role of caregiver^[37]. These tasks affect their daily lives, such as lack of leisure time, loss of freedom to sleep, missing social gatherings and even causing physical problems such as muscle pain. This study used a qualitative and exploratory approach to describe and clarify the caregivers' needs and understand the individuals' perception of the world^[38]. By using a purpose sampling, the participants' choices in terms of gender, age, education level and duration of care varied widely, ensuring the diversity of the sample and contributing to the in-depth and extensive exploration of caregivers' experience needs^[39]. Similarly, an online survey that examined caregivers' unmet needs had the highest changes in daily living that affected caregivers^[40]. Among the factors affecting daily life activities of caregivers (n = 26), 76.9% were influenced by lifestyle and schedule, 65.4% by balancing their own needs and care, and 46.2% by assisting patients to deal with daily needs, such as preparing food, 38.5 % by coping with an impact on work and 34.6 % by helping to take care of own physical and mental health. However, the additional tasks caused by the caregivers affected their daily life and they lost their normal life.

Financial needs are the main needs that affect the daily life activities of caregivers, because psychological functions are related to material items, so economic pressure may increase the burden of caregivers^[40]. At the same time, the lack of funds for equipment makes it difficult to care for patients^[37]. 92.3% of caregivers (n = 26) reported economic needs, and income loss of caregivers and patients was the main cause of economic problems, followed by treatment costs and transportation costs^[40]. Some caregivers also require additional needs, such as meals and transportation^[28]. Caregivers for taking care of tasks can cause their workload to alter or even result in the caregiver becoming unemployed, so they need to other family members to help provide care and financial support^[37]. At this point, the family members are expected to share the burden of care, with the main caregivers' family support being considered a contribution to the caregivers' health ability^[17,41].

14.4% of caregivers (n = 38) used SM to request information on symptoms, treatment options and costs

associated with the illness^[42]. 57.7% of caregivers (n = 26) hope to know what will happen in the future, how to manage the illness of patient and how to provide care for the patient, and 46.2% of caregivers hope to know how to access health services to provide comprehensive care for the patient^[40]. There are also caregivers who describe them lack of knowledge of patient care, making it difficult to provide comfortable care for patients^[37]. In particular, some novices, because they do not have the experience of caregivers and caring knowledge, feel overwhelmed when faced with the problems of care, especially experienced peers to share their experience. Hence, they need a lot of information and knowledge to help them fulfill their caregiver role.

In a SM online communication survey, 12.1% of caregivers (n = 38) sought emotional support [42]. "Caring is very isolated. You do not know who can help you." Caregivers recorded an emotional breakdown during a 2-year care experience and described their needs^[40]. In addition, the caregiver feels ignored, lonely or disappointed, because others do not understand their feelings as a caregiver. Similarly, some caregivers share their anger because people are just concerned about the patient rather than caregivers^[28]. Even when they send out emotional appeals to express their needs, but they do not get the response they deserve. On the contrary, only one study shows that caregivers from Sri Lanka do not have this kind of phenomenon, caring is a full of love, there is no burden^[37]. This may be because of the cultural influence, they think the primary task is to take care of the elderly and the disabled, they have the social security system to support the caregivers, they do not feel isolated.

In a cross-sectional study with a questionnaire, 68% of caregivers (n = 214) used SM for social support^[43]. In addition, six qualitative studies decoding messages from SM found many caregivers seeking help and support by SM^[28,37,40,42-44]. They seek a variety of support, such as asking for illness knowledge from experts, seeking information about caring experiences with experienced caregivers, seeking emotional support from peers, seeking additional financial support, and so on. They seek support in a variety of ways, such as asking for information about patients' illness, consulting with experienced peers about their care, seeking encouragement from peers, and even enjoying the satisfaction of provid-

ing support to other peers. The influence of peer support on caregivers cannot be ignored, so the presence of peers is crucial for caregivers.

4.2 Theme 2: Caregiver usage of the social media interventions

As an innovative and convenient intervention, most caregivers use SM because they can access it anytime and anywhere, and SM can provide caregivers with the information and support they need^[43]. The SM covered in the literature review all show that caregivers use it to gain knowledge and information. SM provides an interactive platform for caregivers to interact with peers or health care professionals, which is completely superior to the traditional way of providing information separately, such as pamphlet, website links. Caregivers connect with peers by sharing information, supplying the information and support to whom demand[40,42-47]. The information shared mainly includes information related to patients and daily life related to themselves. Besides, caregivers share the patients' diagnosis, treatment, examination results, health status as well as the patients' experiences on SM^[28,44]. As well as sharing the disease information, expressing their own views on the lack of knowledge of the disease, calling attention to this kind of disease with timely detection and identification, caregivers also often use SM to share their difficulties in caring for patients as well as their depression and anxiety^[28,40,42,44]. Likewise, there are some caregivers who share their experience in order to help other caregivers to deal with experiences, such as how to face the loneliness of caregivers, and how to deal with the patients' daily life care, how to face the health care of emotional stress^[28,44]. In addition, a small number of caregivers use SM to express their concerns about finances, processing, changes in plans, health problems, and the burden of concerns. They also use SM to share their daily lives and those of their patients^[28,40]. In this sense, SM has become an important platform for caregivers to share information.

All caregivers in this review used SM to gain medical knowledge. Caregivers reach out to professionals and peers by seeking their knowledge, receiving their knowledge, connecting with them, and gaining their support^[40,42,43,45-48]. Some caregivers not only search for medical knowledge, but also interact one-on-one with professionals to obtain timely information^[42,44,45,48,49].

The contents of knowledge mainly include knowledge related to the patients' illness, psychological support, caring skills, discharge guidance, complication prevention, and rehabilitation guidance. Some SM also provide news and entertainment information to make the caregiver feel like a normal person^[50]. Caregivers use SM to promote fund-raising campaigns for themselves and their peers^[28,44]. There are also caregivers who get help from hospitals or agencies through SM^[44]. Additionally, some caregivers use SM to mobilize emotional and logistical support^[42,44,47].

A qualitative analysis after a cross-sectional survey of caregivers' use of SM found that comments (n = 263) from caregivers were the most likely to use SM to encourage others, accounting for 27.7%^[42]. Caregivers use SM to detail patients' survival stories and share inspirational quotes to inspire and encourage other patients^[28,42,44,47]. Caregivers use SM to pray to God and praise God, because every little bit of improvement is a response from God, and to thank everyone who has helped them, for every email, every message, every concern and support^[28,44]. Uniquely, some SM has a reminder function, including daily tasks and drugs^[45,47,48]. Thus, SM provides opportunities for caregivers to access different kinds of social support.

4.3 Theme **3:** The impact of social media interventions on caregivers

SM as an innovative and convenient platform for potential interventions for caregivers. The findings of a cross-sectional survey suggest that SM may be a potential intervention to provide caregivers with the information and support they need. Discover analogous responses by exploring how caregivers use SM^[43]. Similar results came from an online survey in which caregivers expressed satisfaction with the feasibility and acceptability of educational interventions through SM^[49]. Caregivers use SM to communicate with their peers and professionals. As a consequence, SM is an important vehicle for caregivers to provide support and communication^[44]. Although this study was the result of two researchers independently using an iterative strategy to refine early code and themes, as well as discussing topics with their peers at a meeting. However, this conclusion may still have some limitations, as the sample selection only came from Facebook and may not capture the caregiver experience from other SM^[51]. In fact, another study found similar results in a qualitative analysis of logs shared by caregivers on SM^[28]. SM as a communication strategy provides a potential guide to caregivers, help caregivers and nurses to communicate, discuss about the patients' treatment decisions and obtain other support.

A semi-structured interview was proceeded to collect caregivers' views on SM intervention^[46]. It was found that caregivers thought SM intervention was a good helper for sharing information and connecting with others. To prevent caregivers from being overburdened or experiencing serious health problems that lead to additional burdens when participating in the study, the sample excluded both types of caregivers, but also caused a sampling bias because it was part of the population that was more likely to benefit from SM support^[39]. When measuring the effectiveness of SM, active users were found to have an increased sense of competence, less loneliness, and greater family support. The participants in this study had a high school education or above, so the results were not general, especially for the less educated participants. The small sample size (n = 25), and the lack of control group trail, with insufficient test ability, may not be a reliable finding^[39]. Despite this, two RCTs have similar results demonstrated that caregivers improve their ability to care through SM interventions. 86% caregivers (n = 38) agreed with SM-based educational interventions, learning the necessary information to address the challenges that arise in care and developing useful strategies for care^[50]. Caregivers' knowledge of how to deal with difficult situations increased (3.10 \pm 0.76) and their ability to feel about themselves increased $(2.80 \pm 0.81)^{[45]}$. Through the use of SM, caregivers have significantly improved their ability to care for patients and solve problems. As a result, SM as an intervention is worth promoting among caregivers.

SM interventions may reduce caregiver stress. Caregiver access to social support through the use of SM, such as access to health care and self-care, and interaction with peers, connection, and experience sharing, may be an effective way to cope with the stress and anxiety caused by the diagnosis and treatment of patients' diseases^[43]. Although the study used closed-ended questions and answers with multiple options to facilitate participants' understanding of the contents of the questionnaire, it is a cross-sectional survey that only recorded

caregivers' use of SM at a certain point in time, lacking a causal relationship, so the evidence supporting the results was weak^[39]. However, a pilot RCT examining the impact of SM on caregivers showed that SM helps caregivers manage patients' daily needs and provides solutions to the resulting stress^[45]. Although this study used blind data, all Danish caregivers were randomly allocated to the intervention group, while most Polish caregivers were assigned to the control group. These findings should be treated with caution because the sample was misallocated at random^[39].

Caregivers use SM to learn about health information, such as how to deal with sex, anxiety, depression and self-management, which can help them maintain a satisfying relationship with their patients^[50]. Some peers and guests also provided some suggestions for caregivers to manage their own emotions through SM to alleviate the depression and anxiety of caregivers^[44]. The knowledge and information gained through SM can help caregivers solve daily care problems, increase caregivers' self-efficacy and improve depression^[45]. Similarly, a prospective survey about caregivers' SM usage showed that all caregivers agreed that SM interventions could reduce their burden, save their time, reduce depression, improve care, and improve quality of life^[48]. In addition, SM also provides some other information such as news, entertainment, games, and so on, which helps caregivers to maintain a normal life and meet the needs of normal people^[50]. Through the use of SM, caregivers have seen positive improvements in stress, anxiety, depression and more. As a consequence, interventions based on SM can reduce the burden of caregivers and benefit their health.

4.4 Theme 4: The benefits of using WeChat interventions

Interventions through WeChat can help patients and caregivers gain knowledge. A study using technology acceptance model (TAM) as the theoretical framework described caregiver satisfaction with WeChat nursing intervention through quantitative online design using convenient sampling^[49]. Caregivers in this study showed above-average satisfaction in the four aspects of increased knowledge, easy access, helpful management of patients, and access to psychological support. This study adopted TAM theory to effectively perceive two important factors of users' usefulness: use and intend-

ed behavior, and the convenience of use. But this study was an online survey, in which researchers sent 301 surveys and received only 198 responses, a response rate of 65.8%. However, there is a selection bias in the sample because this part of the caregiver that completed the questionnaires may be a more commonly used or satisfied user rather than a broadly representative user^[39].

Interventions through WeChat can provide patients and caregivers with immediate and accurate information. Many elderly people are unable to grasp a large amount of health care information due to memory decline, while WeChat can be used flexibly in text, pictures, videos and other aspects to help users timely and accurate access to or transfer educational information^[47]. Users can view at anytime and anywhere, directly connect medical personnel for one-to-one private interaction, with a high degree of privacy and more accurate information^[49]. Through this online communication and sharing of resources, the current shortage of human resources for health care may be alleviated.

Interventions through WeChat can help nursing staff carryout remote supervision. Zhou et al. noted that stroke rehabilitation programs offered by caregivers in rural China have not improved the functional recovery of stroke survivors^[52]. The result of this study is credible, because this prospective study used a multi-center randomized controlled trial method and collected score of daily life activities of participants using blind analysis data. All of these avoid the selection bias and performance bias, to intervene in the test and each site using standardized semi-structured interview participants and caregivers to evaluate the fidelity of intervention^[39]. It is with regret that results may be due to a decline in patients' participation in exercise after discharge, as caregivers may not provide the same care as professionals, and patients may be reluctant to exercise without supervision, which should be improved by smart phone apps in the future^[52]. Nevertheless, WeChat can be used for one-to-one interactive viewing anytime and anywhere, which is a feasible way to connect participants and medical staff. Through WeChat, professionals can effectively supervise participants and provide knowledge and skills support for caregivers^[49]. However, it also points to clear regional differences in user satisfaction, with urban areas higher than rural areas because rural incomes are relatively poor and Internet access restricted by the economy. Therefore, the intervention of SM on caregivers in rural areas needs to be further studied.

Interventions through WeChat can not only save time for patients and caregivers but also indirectly reduce the economic burden caused by cost. The 4 articles mentioned that caregivers have financial pressure, such as reduced economic income caused by job loss or job change of patients and caregivers, medical expenses, transportation costs to and from the hospital, transportation costs incurred by caring for patients^[28,37,40,53]. In a retrospective descriptive study of the qualitative analysis of the logs, most caregivers expressed financial pressure caused by transportation costs^[28], while interventions of WeChat could reduce the transportation costs for some patients and caregivers to go to the medical institutions for face-to-face consultation.

5. Discussion

This literature review reveals that caregivers have corresponding needs for daily life, financial, knowledge, information, emotions and peers in the process of caring for patients. Through the intervention of using SM, the caregivers acquire plentiful knowledge and information about the care of patients, help solve the care dilemma, improve the care ability and satisfy the sense of self-efficacy. At the same time, caregivers shared their experiences of caring through SM and received encouragement and support from their peers, which reduced negative emotions such as psychological stress, anxiety or depression. Besides, they have received financial, spiritual and emotional support from the community by SM. For caregivers, SM is a good platform to provide required information and knowledge, an important carrier for peer communication and support and a good helper for communication with health professionals. However, social support, economics, anxiety, depression and self-efficacy are all factors that may contribute to the burden on caregivers. Through the identification of the influencing factors of caregiver burden, it is found that caregiver needs, if not met, may cause caregiver burden, and long-term burden may lead to caregiver physical and psychological diseases, thus affecting the health consequences of the patient. Therefore, SM, as a modern and new tool, has demonstrated remarkable functions in the health care field as an intervention medium for professionals and caregivers to develop and deliver content. SM as an intervention can not only provide social support for caregivers, but even have a positive impact on CB. WeChat, as the most frequently used SM in China nowadays, also reflects its unique advantages in the healthcare system. This is especially true in contemporary settings where nursing resources are quite tight, such as assisting doctors and nurses to monitor and manage patients remotely, providing caregivers with knowledge and information support, and so on. Therefore, the intervention of WeChat is expected to assist in solving the gap of continuous caring^[40]. Furthermore, WeChat as an intervention saves time and cost for patients and caregivers to travel to and from the hospital, providing convenience for those who are further away from the hospital.

Articles of caregiver health interventions based on SM included cross-sectional surveys, retrospective quantitative study, qualitative study, RCT, controlled clinical trial (CCT) and mixed study. The selection of articles with a variety of methodological designs is one of the advantages of this review. This is a comprehensive review of research through the diversity of research methods, after all, there is no single paradigm that can answer all the important questions in nursing research, and only through qualitative and quantitative research can we have a better understanding of human health^[54]. Although RCT were included, according to the tool of the Cochrane collaboration by Higgins et al. [55] to assess the risk of bias in randomized trials, different studies had different biases and had a certain influence on the results. so the quality of the researches were not high. In addition, this review includes SM such as Facebook, YouTube, WeChat and so on. Although all of them belong to SM, they have different functions. Therefore, as an intervention, the heterogeneity is high and the results need to be treated with caution^[56]. What's more, there is no systematic evaluation and analysis of all databases.

6. Conclusion

People in different countries use different SM, for example, American tend to Facebook, YouTube, while Chinese use WeChat. This literature review found that SM-based interventions can meet caregivers' needs and have a positive impact on CB of chronic diseases such as cancer, dementia and stroke. As the number of stroke survivors increases, the burden on SCs as a factor that

may threaten the health of caregivers and stroke survivors needs to be given due attention. However, experimental studies of health interventions for SCs through WeChat interventions have been limited. Hence, more quantitative studies are needed in the future to explore the effectiveness of WeChat as an intervention in the CB of stroke survivors. However, it is worth noting that in the systematic literature review on the spread of false information on SM, some health-related information was found to be spread by providers through SM^[57]. Therefore, it is important for professionals to guide caregivers to get the right health information. In the future, professionals such as doctors or nurses should guide caregivers to obtain reliable information through SM, create social support and help caregivers effectively cope with all the challenges in the care process and reduce the burden of caregivers.

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