A SCOPING REVIEW OF ICT-BASED CAREGIVER SUPPORT INTERVENTIONS FOR CHILDREN WITH CANCER

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Abstract: A scoping review of information and communication technology (ICT)-based caregiver support interventions for children with cancer. According to the methodological framework of the scoping review, the research questions were established, Chinese and English literature from January 2000 to March 2019 was searched and screened, relevant studies were identified, data extraction was performed on the included literature, and the research results were collected, summarized and reported. The search obtained 7417 documents, and after screening, a total of 14 articles were included. The publication time, research location, applied ICT technology, intervention objects, intervention tool construction process, function, research design, research duration, result type and theoretical framework applied in the research were summarized and analyzed. Conclusion There are few studies on ICT-based support for caregivers of children with cancer. Existing studies have confirmed that it can provide support to caregivers conveniently and effectively. However, the construction, usability and effectiveness evaluation of ICT-based intervention tools need to be improved, and background management support Insufficient, it is necessary to carry out continuously optimized clinical promotion based on further evaluation of cost-effectiveness.
Keywords: ICT; Caregivers of children with cancer; Scoping review

1 METHOD

The incidence of childhood cancer continues to increase. In 2015, there were 229,000 new cases of childhood cancer in my country, and the incidence rate increased significantly at an annual rate of 2.8% [1]. Parents or grandparents of children with cancer are important caregivers. Their physical and mental health is greatly affected and they are in urgent need of effective support [2]. Traditional interventions mostly use face-to-face or telephone methods, which provide support to caregivers to a certain extent, but are time-consuming and labor-intensive, and the number of caregivers that can benefit is not ideal [3]. Information and communication technology (ICT) has developed rapidly in recent years and is accelerating its integration with medical and nursing care. The technology implementation methods are concentrated on Internet-based telemedicine and mobile medical treatment based on smartphone applications, making intervention more real-time, convenient and accessible [4]. The number of ICT-based caregiver support interventions for children with cancer at home and abroad is limited. Scope reviews are suitable for emerging research fields and focus on presenting the scope and breadth of a type of research, summarizing and disseminating research results, or discovering deficiencies in existing research [5-6]. Therefore, this study adopts a scoping review research method to review ICT-based research on caregivers of children with cancer, with a view to providing a reference for the benefits of ICT in supporting caregivers of children with cancer.

1.1 Establish Research Questions

After a preliminary search of the literature, the research team discussed and determined the research question: What is the current status of research on ICT-based support for caregivers of children with cancer? What are the applied ICTs? How are intervention tools constructed and what functions do they have? How is the intervention evaluated? What theoretical frameworks were applied in the study?

1.2 Identify Relevant Studies and Develop a Literature Search Strategy

Literature published from "January 2000 to March 2019" was searched. The English databases searched included Medline, PubMed, Web of Science, Embase, CINAHL, Springer, and Elsevier. The Chinese databases included Chinese Biomedical Literature Database, China National Knowledge Infrastructure, VIP Chinese Journal Database. The English search uses "information and communication technology, ICT, telehealth, telemedicine, telecare, mobile health, mhealth, ehealth, smartphone, phone, mobile app, mobile application, app, pediatriccancer, childhood cancer-er, caregiver, parent" as the keywords, and the Chinese search uses "information communication Technology, telemedicine, telehealth, mobile health, mobile health, smart care, smartphone applications, mobile phones, applications, childhood cancer, caregivers, parents" are the keywords.

1.3 Literature Screening to Establish Inclusion and Exclusion Criteria

Two researchers independently read titles and abstracts to initially screen the literature, and then read the full text for further screening. Inclusion criteria: (1) Research on applying ICT to provide support for caregivers of children with cancer and promote caregivers' physical and mental health; (2) Constructing ICT intervention tools, or evaluating the usability of tools, or evaluating the effectiveness and cost-effectiveness of interventions Research. Exclusion criteria: (1) Review studies; (2) Journal articles or conference abstracts without full text.

1.4 Extract Data

Determine the information that needs to be extracted and develop tables for organizing and summarizing the data.

1.5 Collect, Summarize, and Report Research Results

The scope, nature, and distribution of included studies were summarized, and the extracted data were presented in tabular form.

2 RESULTS

A total of 7417 documents were retrieved, of which 5723 remained after removing duplicate documents. After reading the titles and abstracts and removing irrelevant documents, 32 remained. 11 journal papers and conference abstracts without full text, 2 reviews, and 5 incompatible intervention target categories were removed. A total of 14 documents were included. 14 studies were published from 2004 to 2018 and were conducted in the United States (n=2), Australia (n=9), and China (n=3). The sample size of caregivers of children with cancer as intervention subjects ranges from 1 to 300, and the study duration ranges from 10 days to 18 months. The applied ICT includes: online online videos (n=8), smartphone applications (n=5), and online websites (n=1). The research design included qualitative research (n=1), mixed research (n=5), and quantitative research (n=8); 3 of the 5 randomized controlled trials (RCT) did not report the research results. research plan. The research results cover application construction (n=3), usability evaluation (n=7), effectiveness evaluation (n=6), and cost-benefit analysis (n=4). Only 4 studies mentioned the theoretical framework on which the intervention program was constructed.

3 DISCUSSION

3.1 Current Status of Research on ICT-Based Caregiver Support for Children with Cancer

The development of ICT and the Internet has made it possible to provide convenient support for caregivers of children with cancer. Since 2004, the Bensink research team has focused on caregivers of children with cancer who receive hospice care and caregivers of children with cancer who are newly diagnosed and in the first home interval after treatment, and have conducted a series of caregiver support studies based on online video calls; Through remote information and psychological support, the communication cost between caregivers and medical staff is reduced, the convenience and efficiency of communication are improved, the caregivers are encouraged to provide high-quality care for children during the home interval, and the caregivers are provided with psychological and psychological support. Emotional support. Wakefield et al. conducted online video therapy for parents of children with cancer in three aspects: problem coping, disease acceptance, and social and interpersonal reconstruction, which effectively reduced the parents' fear of disease recurrence and improved their psychological state. With the continuous development of ICT, researchers have begun to pay attention to smartphone applications, whose functions include information support, psychological support, appointment for medical treatment, emergency call for help, etc. Educational information can be directly stored in the application, reducing the need for medical staff to answer the same consultation questions. Repeated answers will save medical resources. Wang et al. used smartphone applications and WeChat public account platforms to provide home care, social support, knowledge education and other services to the caregivers of children, which significantly reduced the anxiety and uncertainty of the disease among the parents of the children, and improved the parents' social functions and their understanding of the disease. The understanding of knowledge related to care is improved and the need for knowledge is reduced, the response to the entire intervention is good, and the overall satisfaction with care is good. In summary, it can be seen that ICT-based intervention for parents of children with cancer is effective, convenient and accessible, but the number of interventions is small and limited to the clinical testing stage, and has not yet achieved widespread clinical application. to meet the needs of personalized services and precision medicine. Therefore, actively responding to the country's call for "Healthy China", integrating the advantages of telemedicine and mobile medicine, leveraging ICT and big data, integrating advanced data mining technology, and providing more precise support to caregivers will be an important development in future related research. direction.

3.2 Limitations and Improvement Directions of Research on ICT-Based Caregiver Support for Children with Cancer

3.2.1 Support tool building for inclusion in research
There are various methods for building support tools, including improvement of original programs based on experience, literature analysis, interviews with target users, focus group discussions, and expert consultation. Four studies referred

to relevant theoretical frameworks when constructing tool content. Wakefield et al. matched each intervention module with cognitive behavioral theory, which is an important basis for the effectiveness of their intervention. Therefore, relevant theories should be considered when designing the content of support tools to improve their scientific nature and effectiveness. At the same time, it is recommended to understand the real needs of caregivers based on literature and interviews with target users. After classifying the needs, imagine the application functions, and improve the functional assumptions under the guidance of caregivers, clinical medical staff and hospital stakeholders to improve the tool. practicability, usability and effectiveness, and ultimately promote clinical implementation.

3.2.2 Usability evaluation of support tools

The usability of support tools is a necessary condition for their clinical effectiveness. Seven of the studies included in this review involve usability evaluation, all of which are small-sample non-experimental studies, including trial feedback from target users, evaluation by medical staff and inspection by technicians. The usability laboratory is currently one of the important places for usability evaluation. It is recommended that on the basis of the participation of caregivers, medical staff and hospital stakeholders, it is recommended to work with ICT professional and technical personnel to conduct usability evaluation based on the "effectiveness and efficiency" in the ISO9241 standard] and satisfaction" three usability indicators, a simple formative usability evaluation is carried out in order to evaluate the user interface design wireframe and eliminate obvious usability problems; a comprehensive formative usability evaluation is to evaluate the real usability of each functional module; a summative usability evaluation , to evaluate the time it takes users to complete specific tasks, the fluency and complexity of input data, etc. Summarize the usability evaluation results and feed them back to the technical development team for tool modification and continuous optimization.

3.2.3 Support evaluation of the effectiveness of interventions

This study included 3 effectiveness evaluations of reported results[9] and 3 research plans that have not yet reported results . The research designs all adopted RCT design, with sample sizes ranging from 45 to 300, and 2 studies confirmed the intervention. effectiveness. Given that ICT-based caregiver support for children with cancer is still in its early stages of exploration, mixed research is a more recommended research design because mixed research can not only confirm the effectiveness of the intervention through data comparison, but also further develop it through qualitative interviews. Supplement and explain quantitative results, and provide open access to directions for improvement of the intervention, providing a basis for optimizing tools and improving intervention effects.

3.2.4 Support cost-effectiveness evaluation of interventions

The premise for clinical promotion of intervention programs is that they are effective and cost-saving. In the cost-effectiveness evaluation of remote intervention based on video calls , Barnford et al. [10] and Bensink et al. [8] evaluated fixed and variable equipment, infrastructure costs, and hospital equipment. , statistics on home equipment, staff costs (care coordinators, technicians), scheduled outpatient consultation costs and transportation costs for children with cancer and caregivers confirmed that video call-based interventions are more economical. Studies based on smartphone apps and online websites did not evaluate cost-effectiveness. The evaluation of cost-effectiveness is crucial. It is recommended that follow-up research be conducted on cost-effectiveness modeling to compare indicators such as equipment investment, personnel investment, implementation cost and the ratio of reduction in treatment costs.

3.2.5 Support clinical implementation and promotion of intervention

After meeting the above conditions, maintaining long-term appeal to target users, that is, increasing user stickiness, is an important condition for the clinical implementation and promotion of ICT intervention. Updating and providing targeted and precise support as caregivers' support needs change is an effective way to increase user stickiness. In online video call intervention, the medical team and caregivers talk remotely to solve caregiver problems in a targeted manner . Medical staff and caregivers have a clear understanding of the relationship. Great interactivity and interactivity. Only three of the later interventions using mobile phone applications (the same program) designed interactive modules to achieve non-real-time interaction between caregivers and medical staff. The realization of interaction and interaction between caregivers and medical staff requires the effective support of a stable back-end medical team. Therefore, it is necessary to form a back-end team that includes hospital medical staff, hospital stakeholder groups, community medical staff and technical personnel. The stability of the team is more Strong support from relevant policies and systems is needed.

4 CONCLUSION

The convenience, feasibility and effectiveness of providing support to caregivers of children with cancer based on ICT have been initially confirmed, but the number of relevant studies is small, there are still deficiencies in the construction, usability and effectiveness evaluation of support tools, and there is a lack of cost-effectiveness of the intervention. There is also a lack of long-term backend support from the medical professional team. At present, China is vigorously developing a hierarchical diagnosis and treatment system. Therefore, with the support of ICT, it integrates the advantages of telemedicine and mobile medicine to build a "trinity" model with families as the main body, communities as the hub, and central hospitals as the core, integrating cloud computing, big data, etc. Technology, mining process data and outcome data, and providing more accurate support for caregivers will be the only way to implement scientific research into clinical practice and provide long-lasting and effective support for caregivers of children with cancer.

COMPETING INTERESTS

The authors have no relevant financial or non-financial interests to disclose.

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