Health Literacy and Internet Health Information Seeking Among Caregivers of Pediatric Cancer Patients: A Postprint Study

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Abstract

Background Cancer is the second leading cause of death among children. The health literacy level of caregivers of pediatric cancer patients not only affects their ability to search for internet health information, but also has a certain impact on the health outcomes of the children. Few studies have explored the relationship between health literacy and internet health information searching among caregivers of pediatric cancer patients.

Objective To explore the relationship between health literacy and internet health information searching among caregivers of pediatric cancer patients, and to analyze the factors influencing caregivers' internet health information searching.

Methods From May to August 2021, using purposive sampling in three hospitals in Shandong Province, and from June to August 2022, using cluster sampling and snowball sampling through the Shenzhen Henghui Public Welfare Foundation in Guangdong Province, 424 caregivers of pediatric cancer patients were selected as study subjects. A basic characteristics questionnaire and a health literacy questionnaire were administered, and whether internet health information searching was conducted was confirmed through caregivers' subjective responses. Point-biserial correlation analysis was used to examine the correlation between health literacy and internet health information searching among caregivers of pediatric cancer patients; binary Logistic regression (forward stepwise regression based on maximum likelihood estimation) was used to analyze the influencing factors of caregivers' internet health information searching.

Results The scores of health literacy among caregivers of pediatric cancer patients in the four dimensions of "feeling understood and supported by healthcare professionals", "evaluation of health information", "ability to actively interact with healthcare professionals", and "having sufficient understanding of health information and knowing what to do" were

(2.60$±0.30), (2.76±0.34), (3.91±0.32), *and*(4.07±$0.30), respectively; the proportions of high health literacy were 56.13%, 63.21%, 62.97%, and 35.61%, respectively; the dimension score of "feeling understood and supported by healthcare professionals" was negatively correlated with internet health information searching (r=-0.161, P<0.01), and the dimension score of "having sufficient understanding of health information and knowing what to do" was positively correlated with internet health information searching (P<0.05). Educational level of junior high school, high school/technical secondary school, university/college or above, one-child family, "evaluation of health information", and "ability to actively interact with healthcare professionals" were promoting factors for caregivers' internet health information searching (P<0.05); "feeling understood and supported by healthcare professionals" was a hindering factor for caregivers' internet health information searching (P<0.05).

Conclusion Most caregivers of pediatric cancer patients will conduct internet health information searching, and higher educational level, being a one-child family, stronger ability to evaluate health information, maintaining active interaction with healthcare professionals, and rarely feeling understood and supported by healthcare professionals can promote the occurrence of internet health information searching behavior among caregivers of pediatric cancer patients. The government and relevant departments should actively carry out health education actions targeted at caregivers of pediatric cancer patients to improve their health literacy level and ability to use the internet to search for health information.

Full Text

Study on the Relationship Between Health Literacy and Online Health Information Searching Among Caregivers of Pediatric Oncology Patients

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Abstract

Background: Cancer is the second leading cause of death among children. The health literacy level of caregivers for pediatric oncology patients not only affects their ability to search for health information online but also influences health

outcomes for the children under their care. However, few studies have examined the relationship between health literacy and online health information searching among this population.

Objective: To explore the relationship between health literacy and online health information searching among caregivers of pediatric oncology patients and to analyze the factors influencing caregivers' online health information search behavior.

Methods: A total of 424 caregivers of pediatric oncology patients were recruited through purposive sampling from three hospitals in Shandong Province between May and August 2021, and through cluster sampling and snowball sampling in Guangdong Province via the Shenzhen Henghui Public Welfare Foundation between June and August 2022. Data were collected using a basic characteristics questionnaire, the Health Literacy Questionnaire (HLQ), and caregivers' self-reported responses regarding whether they conducted online health information searches. Point-biserial correlation analysis was used to examine the relationship between health literacy and online health information searching, while binary logistic regression (forward stepwise regression based on maximum likelihood estimation) was employed to analyze influencing factors.

Results: Caregivers' health literacy scores across four dimensions were: "Perceived Understanding and Support from Healthcare Professionals" (2.60$\pm$0.30), "$Evaluation of Health Information$"(2.76$\pm$0.34), "$Ability to Actively Interact with Healthcare Pro$ The proportions of caregivers with high health literacy in these dimensions were 56.13%, 63.21%, 62.97%, and 35.61%, respectively. The "Perceived Understanding and Support from Healthcare Professionals" dimension was negatively correlated with online health information searching (r=-0.161, P<0.01), while the "Knowing Enough About Health Information and What to Do" dimension was positively correlated (r=0.102, P<0.05). Education levels of junior high school, high school/vocational school, and college/junior college or above; being from a one-child family; higher scores in "Evaluation of Health Information"; and higher scores in "Ability to Actively Interact with Healthcare Professionals" were facilitating factors for online health information searching (P<0.05). In contrast, higher scores in "Perceived Understanding and Support from Healthcare Professionals" were a hindering factor (P<0.05).

Conclusion: The majority of caregivers of pediatric oncology patients engage in online health information searching. Higher education levels, being from a one-child family, stronger ability to evaluate health information, more active interaction with healthcare professionals, and rarely feeling understood and supported by healthcare professionals promote online health information searching behavior. Governments and relevant departments should actively implement health education initiatives targeting caregivers of pediatric oncology patients to improve their health literacy and capacity to use the Internet for health information searching.

Keywords: Neoplasms; Child; Caregivers; Health literacy; Online health infor-

mation search; Correlation study

Introduction

Cancer is the second leading cause of death among children worldwide [1-2]. In China, approximately 40,000 new pediatric cancer cases are diagnosed annually, with incidence rates continuing to rise. Due to insufficient disease awareness among patients and caregivers and the lack of early screening mechanisms, many pediatric cancer patients miss optimal treatment windows [3]. Caregivers play a critical role throughout the treatment and rehabilitation process, serving as intermediaries who obtain health information from medical staff and communicate treatment information to healthcare providers, thereby assisting in clinical decision-making. This role demands a certain level of health literacy [4-5]. Research has shown that low health literacy is not only associated with poor health behaviors and outcomes but also constitutes a significant factor contributing to higher premature mortality rates, non-adherence to medical advice, and increased direct and indirect healthcare costs [6].

The digital era has made searching for health information on the Internet the mainstream approach [7]. As a coping strategy, online health information searching helps address health-related problems and alleviate concerns and stress associated with health issues [8]. Studies indicate that the Internet is a primary source of information for chronic disease patients and plays an important role in their health management [9-10]. Patients with higher health literacy may be better equipped to search for and select online health information [9-10]. One study demonstrated significant relationships between health literacy, online health information searching, and caregiving strategies among cancer patient caregivers [11]. However, most existing research focuses on adult cancer patients, with few studies examining the health literacy levels and online health information searching behaviors of pediatric oncology patient caregivers or analyzing the relationship between these factors. Therefore, this study aims to investigate the health literacy level of caregivers of pediatric oncology patients, explore its correlation with online health information searching, and identify the main factors influencing their online search behavior, thereby providing a reference basis for pediatric cancer prevention and control and for improving caregiver health literacy.

Methods

1.1 Study Subjects

Using purposive sampling, we recruited caregivers of pediatric hematologic and solid tumor patients from three tertiary Grade A hospitals in Shandong Province (Shandong Cancer Hospital, Qilu Hospital of Shandong University, and Qilu

Children's Hospital of Shandong University) between May and August 2021. Inclusion criteria were: patients under 18 years of age; diagnosed with cancer; no severe visual, hearing, cognitive impairments, or psychiatric history; and voluntary participation with informed consent. A total of 305 questionnaires were distributed, with 303 valid questionnaires returned (valid response rate: 99.34%).

Between June and August 2022, through the Shenzhen Henghui Public Welfare Foundation's "Lian'ai Project," we recruited caregivers of pediatric leukemia patients in Guangdong Province using cluster sampling in Heyuan City and snowball sampling in Yunfu and Shanwei Cities. Inclusion criteria were: patients under 18 years of age; household registration in Heyuan, Shanwei, or Yunfu City; basic medical insurance location matching household registration; treatment phase in maintenance or discontinuation period; and voluntary participation with informed consent. A total of 121 questionnaires were distributed, with 121 valid questionnaires returned (valid response rate: 100%). After excluding questionnaires with missing data, duplicates (keeping only one based on IP address), logical errors, or not meeting inclusion criteria, the final sample comprised 424 caregivers.

1.2 Survey Content

The survey included three components: a basic characteristics questionnaire, the Health Literacy Questionnaire (HLQ), and questions about online health information searching behavior.

The self-designed basic characteristics questionnaire collected information on gender, age, marital status, education level, occupation type, long-term residence location, number of permanent household residents, one-child family status, monthly household income after diagnosis, and patient tumor type.

The HLQ, developed by Osborne et al. in 2013, is a universal scale applicable to low- and middle-income countries, comprising 9 dimensions with 44 items. With authorization from Osborne, we used the Chinese version translated through standard procedures, which has demonstrated good reliability and validity [12]. We selected four dimensions that strongly reflect caregivers' abilities to engage in healthcare processes: "Perceived Understanding and Support from Healthcare Professionals," "Evaluation of Health Information" (referring to individuals' ability to judge whether health information is useful to them), "Ability to Actively Interact with Healthcare Professionals," and "Knowing Enough About Health Information and What to Do." These dimensions contain 4-6 items each, totaling 19 items. The first two dimensions use a 4-point scale ("strongly disagree" to "strongly agree" scored 1-4), while the latter two use a 5-point scale ("very difficult" to "very easy" scored 1-5). High health literacy level for each dimension was determined by mean scores: >2.6 for "Perceived Understanding and Support," >2.76 for "Evaluation of Health Information," >3.91 for "Ability to Actively Interact," and >4.07 for "Knowing Enough About Health

Information" [13]. In this study, the internal consistency coefficients for the four dimensions ranged from 0.878 to 0.911.

Online health information searching was determined by caregivers' responses to the question: "Have you obtained knowledge about your child's health care through the Internet?" An affirmative answer indicated engagement in online health information searching.

1.3 Quality Control

Strict quality control measures were implemented throughout all survey stages. Before the survey, participants' informed consent was obtained. During the survey, participants' autonomy was respected, and they could withdraw at any time. After the survey, investigators checked questionnaires for logical consistency and completeness.

1.4 Statistical Analysis

Data were analyzed using Excel 2019 and SPSS 26.0. Categorical data were expressed as relative numbers, with between-group comparisons using ^{2} tests. Normally distributed continuous data were expressed as ($\bar{x}\pm s$), while non-normally distributed data were expressed as M(QR). Point-biserial correlation analysis examined the relationship between health literacy and online health information searching. Influencing factors were analyzed using binary logistic regression (forward stepwise regression based on maximum likelihood estimation). The significance level was set at α=0.05.

Results

2.1 Basic Characteristics of Caregivers

The study included 424 caregivers of pediatric oncology patients with a mean age of $(36.3\$\pm6.1)years.Themajoritywerefemale(n = 303, 71.46\pm\$1.4)$ permanent household residents. Monthly household income after diagnosis was 4,000 (0, 6,000) yuan. More than half engaged in online health information searching (n=235, 55.42%). The most common tumor type was hematologic (n=274, 64.62%).

No statistically significant differences in online health information searching were found by gender, marital status, or monthly household income after diagnosis (P>0.05). However, significant differences were observed by age, education level, occupation type, residence location, number of permanent household residents, one-child family status, and patient tumor type (P<0.05). See .

2.2 Health Literacy Status of Caregivers

Caregivers' health literacy scores and levels across the four dimensions are shown in . The proportions of caregivers with high health literacy, from highest to lowest, were: "Evaluation of Health Information" (63.21%), "Ability to Actively Interact with Healthcare Professionals" (62.97%), "Perceived Understanding and Support from Healthcare Professionals" (56.13%), and "Knowing Enough About Health Information and What to Do" (35.61%).

2.3 Correlation Between Health Literacy and Online Health Information Searching

The "Perceived Understanding and Support from Healthcare Professionals" dimension was negatively correlated with online health information searching (r=-0.161, P<0.01), while the "Knowing Enough About Health Information and What to Do" dimension was positively correlated (r=0.102, P<0.05). No linear correlations were found for "Evaluation of Health Information" (r=0.006, P>0.05) or "Ability to Actively Interact with Healthcare Professionals" (r=0.073, P>0.05).

2.4 Influencing Factors of Online Health Information Searching

Binary logistic regression (forward stepwise regression based on maximum likelihood estimation) was performed with online health information searching as the dependent variable and caregivers' gender, age, marital status, education level, occupation type, residence location, number of permanent household residents, one-child family status, monthly household income after diagnosis, patient tumor type, and the four health literacy dimensions as independent variables. Variable assignments are shown in .

The results indicated that six variables entered the regression equation: education level, one-child family status, patient tumor type, "Perceived Understanding and Support from Healthcare Professionals," "Evaluation of Health Information," and "Ability to Actively Interact with Healthcare Professionals." The model showed good fit (^{2}=4.813, P=0.777). Education levels of junior high school, high school/vocational school, and college/junior college or above; being from a one-child family; higher scores in "Evaluation of Health Information"; and higher scores in "Ability to Actively Interact with Healthcare Professionals" were facilitating factors for online health information searching (P<0.05). In contrast, higher scores in "Perceived Understanding and Support from Healthcare Professionals" were a hindering factor (P<0.05). See .

Discussion

This study investigated caregivers of pediatric oncology patients from Shandong and Guangdong provinces, describing their health literacy levels and online

health information searching behaviors and analyzing their interrelationship to provide reference for improving caregiver health literacy and pediatric cancer prevention and control.

Our findings revealed that among the four health literacy dimensions, the lowest proportion of high health literacy was in "Knowing Enough About Health Information and What to Do" (35.61%), while other dimensions showed moderate levels. This may be because caregivers with lower education levels have limited access to health information channels and cannot fully understand or maximize the use of health information, restricting health literacy improvement [14]. Indeed, 51.18% of caregivers in this study had education levels of junior high school or below. Previous research has shown that higher education levels increase the probability of online health information searching [15], consistent with our results. Caregivers with lower education levels, constrained by knowledge and skills, exhibit lower ability to screen and trust online health information, resulting in less frequent Internet use for health information [16]. This suggests that healthcare professionals should focus on improving caregivers' cognitive abilities regarding health literacy and their skills in using the Internet to search for health information, while also developing their own capacity to assess health literacy to accurately identify caregivers with low health literacy [17-18]. Health education initiatives should specifically target caregiver groups who may not benefit from online health information.

This study found that higher scores in "Evaluation of Health Information" increased the likelihood of online health information searching. The vast amount of online health information varies in quality and utility, but when caregivers possess strong evaluation abilities, they can effectively discern and filter information, obtain professional medical services under proper guidance, and thereby improve patient health outcomes. This aligns with findings from Li et al. [19]. Additionally, the "Ability to Actively Interact with Healthcare Professionals" positively influenced online health information searching. This may occur because caregivers cannot understand certain medical terminology or doubt consultation results, prompting them to seek more disease-related knowledge, or because they wish to participate in medical decision-making through active communication with healthcare professionals [20-22].

Our study also showed that caregivers from one-child families were more likely to use the Internet to search for health information compared to those from multi-child families, similar to findings by Rebecca Jaks et al. [23]. This may be because caregivers in one-child families can concentrate more time and energy on a single child. Moreover, as Internet penetration increases in China, obtaining health information online offers timeliness and convenience, greatly meeting caregivers' information needs and providing a platform for health information sharing. However, this relationship warrants further investigation. We also found that stronger "Perceived Understanding and Support from Healthcare Professionals" decreased the probability of online health information searching, consistent with studies by Lim et al. [24] and Chu et al. [25]. The likely reason

is that when healthcare professionals provide adequate care and support and address problems before and after consultations, caregivers have less need to seek health information from other sources.

In summary, the speed and convenience of online health information can compensate for limitations in offline healthcare and better serve patients. Higher health literacy levels increase the probability of online health information searching behavior. Currently, both health literacy levels and online health information searching abilities among caregivers of pediatric oncology patients in China need improvement. We recommend focusing on the channels, frequency, and content of caregivers' online health information searching, and conducting targeted education campaigns to improve their abilities to search for, understand, evaluate, and apply health information to solve health problems, thereby promoting the efficient use of online health information. Second, governments and relevant departments should strengthen top-level design, enhance network supervision, and crack down on false and fraudulent information to create a favorable online environment. Finally, healthcare professionals should actively adapt to doctor-patient communication models in the Internet era.

This study has several limitations. The sample size was relatively small, and sampling was limited to Shandong and Guangdong provinces, which may restrict sample representativeness. Additionally, the assessment of health literacy among pediatric oncology patient caregivers did not use a disease-specific scale, which may introduce measurement bias. Future research should conduct multi-regional, large-scale studies and develop or adapt health literacy scales specifically for caregivers of pediatric oncology patients to more comprehensively analyze the relationship between health literacy and online health information searching.

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Note: Figure translations are in progress. See original paper for figures.