



Association between eHealth literacy, diabetic behavior rating, and burden among caregivers of children with type 1 diabetes: Cross-sectional survey study

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ABSTRACT

Objective: The purpose of this study was to clarify the relationship between eHealth literacy, diabetic behavior rating, and caregiving burden among caregivers of children with type 1 diabetes mellitus (T1DM).

Methods: A questionnaire-based cross-sectional study of 143 primary caregivers of T1DM was conducted. Electronic health literacy was quantified using the Chinese version of the eHealth Literacy Scale (eHEALS). Their diabetic management behavior rating and caregiving burden were measured by Diabetes Behavior Rating Scale-Parent Version (DBRS-P) and Zarit Burden Interview (ZBI), respectively. Pearson correlation analysis was used to estimate the relationship between the above variables.

Results: Only 54 (37.76%) caregivers qualified by eHEALS scale, with a total score of 30.07 ± 4.54 out of 40. A positive correlation between DBRS-P scores and the scores of eHEALS (Pearson correlation coefficient $r = 0.226$, $P = 0.007$) and a negative correlation between ZBI and eHEALS scores ($r = -0.166$, $P = 0.047$) were observed.

Conclusions: The eHealth literacy level of caregivers of children with T1DM in China remains to be improved. Caregivers with higher eHealth literacy had better diabetic management behaviors and less caregiving burden.

Implications to practice: This study suggests that hierarchical electronic health-based interventions should be designed according to the different levels of eHealth literacy of individuals, to enhance the ability of caregivers with different eHealth literacy levels to fully utilize eHealth resources to improve their daily disease management skills and reduce their burden when caring for T1DM children. In addition, improving eHealth literacy of caregivers for children with T1DM can be one of the important ways to enhance the effectiveness of electronic health-based programs designed for them.

Introduction

Type 1 diabetes mellitus (T1DM) is an autoimmune disease caused by the interaction of genetic, environmental, and other factors (Mayer-Davis et al., 2018) affecting approximately 500,000 children (<15 years) worldwide (International Diabetes Federation, 2021). It is one of the most common and severe chronic metabolic diseases in children and adolescents and also a disease that requires very strict disease management, which is a great challenge for their caregivers and places a heavy nursing burden on them (Tong et al., 2022).

Parents are the main caregivers in charge of disease management for pediatric patients with T1DM in China, and caregivers' involvement in diabetes management was a strong determinant of their optimal glyce-mic control (Ogugua et al., 2021). These caregivers need to deal with a variety of issues related to diabetes management, including use of technology for T1DM management, adjustment of insulin use in case of abnormal blood glucose level, poor nutritional control and manage-ment, control of exercise amount and time, drug selection, combined use of different drugs, and the burden on their own psychological well-being (Lu et al., 2020; Tong et al., 2021). The diabetes behavior rating of

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caregivers is an important index to evaluate their disease management behavior and is closely related to the prognosis of children (Iannotti et al., 2006).

As the disease management of children with T1DM is a tedious and demanding task, caregivers are facing a certain burden of care (Kobos & Imiela, 2015). They often struggle with the glycemic management issues of children and have difficulty providing daily care and making health-related decisions (Lu et al., 2020). Therefore, it is important for them to constantly update enough information related to disease treatment and care management. A qualitative study on parents' experience of caring for children with T1DM in mainland China showed that they have a strong desire for information (disease-related information, home care information, and channels of information acquisition) (Tong et al., 2021). The lack of adequate and up-to-date disease management information among caregivers is a significant factor contributing to their burden and poor diabetes management behaviors. Higher caregiving burden is associated with higher risk for depression and poorer well-being of caregiver (Capistrant et al., 2017). Poor diabetes management behaviors will lead to suboptimal blood glucose control and early onset of diabetes-related complications in children (McLarty et al., 2020).

With the flourishing development of electronic health (eHealth) technology, the Internet is currently one of the most widely used tools for easy access to healthcare and disease management information, providing caregivers with unprecedented access to an enormous amount of eHealth information (Norman, 2011). EHealth literacy refers to the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem (Norman & Skinner, 2006a). As the use of eHealth grows rapidly, the concept of eHealth literacy becomes more important than ever to understand and advance (Kim et al., 2023; Levin-Zamir & Bertschi, 2018). Although the development of eHealth has brought great convenience to information seekers, the implementation of eHealth also puts forward high requirements on their eHealth literacy as they are facing new disparities and challenges (Smith & Magnani, 2019), such as the need to master the skills related to the use of electronic devices. In addition, the quality of diabetes health information on websites is far from sufficient (Kong et al., 2021; Wu et al., 2019), and they need to be able to identify the authenticity of eHealth information to avoid being misled, especially from sham publicity.

Some previous studies have focused on the status of eHealth literacy of different populations (Han et al., 2018; Verma et al., 2022), while paid less attention to their specific preferences or needs when seeking eHealth information, leading to a lack of specificity in instructing patients or their caregivers to use eHealth. In addition, the relationship between eHealth literacy, health-maintaining or promoting behaviors and disease care burden remains to be discovered. Therefore, this study aims to first further investigate caregivers eHealth information-seeking preferences and then, to clarify the relationship between caregivers' eHealth literacy status and their diabetic behavior rating and caregiving burden, as an important supplement to previous studies. Understanding caregivers' eHealth information-seeking preferences, the relationship between eHealth literacy and their diabetic behavior rating and caregiving burden will equip professionals with the knowledge and confidence to enhance eHealth literacy promotion measures for caregivers, facilitate their diabetes-specific management behaviors, and reduce caregiving burden. Ultimately, both children with T1DM and their caregivers can have better health outcomes.

Methods

Participants

The cross-sectional data were collected from January 2022 to August 2022 using Wenjuanxing (an online data collection platform) through a convenience sampling method. We recruited primary caregivers of

children with T1DM from the Diabetes Education Center, the National Endocrine and Metabolism Centre, and the endocrinology department at a Pediatric Specialist Hospital. Inclusion criteria were (1) having a child (age ≤ 14 years old) who were diagnosed with T1DM; (2) the primary caregiver of the child; (3) using electronic devices such as computers, smartphones, or tablets. Subjects were excluded if the child had other serious acute or chronic diseases simultaneously.

Recruitment

Each study center has a trained diabetes specialist nurse to identify potential participants. The diabetes specialist nurses explained this study's purpose, along with the procedure of data collection, and checked for the participants' eligibility. When potential participants met the criteria and voluntarily agreed to participate in the study, they were sent a QR code or link to the questionnaire. Electronic informed consent forms were obtained prior to participating in the survey.

Measurements

Sociodemographic characteristics

Recorded demographic parameters included age and diabetes duration of children, age, sex, residence, degree of education, family monthly income of primary caregivers.

Online health information seeking preferences

Online health information-seeking preferences were evaluated with a self-designed questionnaire (with single or multiple choice questions). The questionnaire was designed with reference to two caregivers of children with T1DM (with a disease course of >5 years) and two clinical diabetes education experts.

The main items included: How often do you seek T1DM-related health resources online? Which eHealth information search tool do you usually use? What aspects of T1DM-related eHealth information do you often look for? What types/forms of online health resource services do you usually use?

eHealth Literacy scale (eHEALS)

In 2006, Skinner and Norman systematically investigated the features that led to eHealth literacy and developed the eHealth Literacy scale (eHEALS) (Norman & Skinner, 2006b). The 8 main evaluation items include the application ability of network health information and services (items 1–5), information evaluation ability (items 6 and 7), and decision-making ability (item 8). The scale adopts the Likert 5-point scoring method (1 = strongly disagree, 5 = strongly agree). The total score of the scale is the sum of 8 items, resulting in a range from 8 to 40. The higher the score, the higher the level of eHealth literacy, and a total score of 32 or more is considered qualified, meaning that the individual has qualified skills and abilities to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem (Meng & Shen, 2018; Chang & Schulz, 2018). This study used the Chinese version of eHEALS scale translated by Guo et al. with a Cronbach's alpha of 0.913 (Guo et al., 2013).

Diabetes Behavior Rating Scale - Parents version (DBRS-P)

The Diabetes Behavior Rating Scale is a suitable measure of conventional and flexible disease management behavior of T1DM modified by Iannotti et al. (2006), including parents version and adolescents version, respectively. The Chinese version of DBRS was translated and revised by XU et al. (Xu et al., 2018; Zhu et al., 2018). The scale comprehensively covers the main aspects of T1DM management including management adjustment (8 items), blood glucose monitoring and control (10 items), daily basic management (14 items) and insulin injection (insulin pen: 4 items, insulin pump: 5 items), scoring using the Likert rating method. When the number of options is 5 (score 0–4), the

score is divided by 4. When there are 6 options (score 0–5), the score is divided by 5. Finally, an average score of all items was calculated. The average score ranged from 0 to 1, with higher scores indicating the higher disease management ability. The Cronbach's alpha of the Chinese DBRS-P in this study was 0.92.

Zarit Burden Interview (ZBI)

The Zarit Burden Interview (ZBI) is one of the most widely used measurement tools to study caregiving burden (Zarit et al., 1980). It can comprehensively reflect the health status, mental state, economic, and social life of caregivers. The Chinese version of the ZBI consists of 22 items, which belong to dimensions of personal burden and role burden, respectively (Lu et al., 2009). The scale applies the Likert 5 scoring method, ranging from “none” (0) to “always” (4). The total score ranged from 0 to 88, with a higher score implying a heavier caregiving burden. A score of <20 indicates no burden, a score of 21–40 indicates mild-to-moderate burden, and a score of ≥ 41 indicates high to severe burden (Tao et al., 2022). The internal consistency of the scale was 0.875 (Cronbach's alpha).

Ethical considerations

This study was conducted in accordance with the Declaration of Helsinki, and this paper adheres to Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines. All participants gave informed consent in electronic format. All of the personal information was recorded and kept confidential in the hospital's computer system, which is password protected. Only designated researchers have access to the survey data. Approval for the study protocol was granted by the research ethics committee of the First Affiliated Hospital of Nanjing Medical University (2022-SR-130).

Statistical analysis

Categorical and continuous data were described using descriptive statistics (mean, standard deviation [SD], frequencies, and percentages). Pearson correlation analysis was used to clarify the relationship between eHealth literacy and diabetic behavior rating and caregiving burden. All statistical analyses were performed with SPSS version 26.0 (IBM Corp., Armonk, NY, USA). P values ≤ 0.05 were considered statistical significant.

Results

Demographic characteristics and eHealth related preferences

One hundred eighty caregivers were approached, and 145 agreed to participate. Two caregivers were excluded because of reporting never searching for electronic health information and incomplete responses to the questionnaire, respectively. Finally, the results of 143 caregivers were included in the analysis. The sociodemographic information of the study sample is shown in Table 1. The mean age of the caregivers was 37.2 years (range: 28–52, SD: 4.7). The primary caregiver for most children (119/143, 83.2%) was their mother. There were 106 (74.1%) participants had high school education or above. The mean age of the children with T1DM was 8.8 years (range: 2 to 14, SD: 3.1) with an average diabetes duration of 2.7 ± 2.3 years.

The participants tended to favor smartphones (142/143, 99.30%) over computers (32/143, 21.68%) and tablets (22/143, 15.38%) when searching for eHealth information. The majority (86/143, 60.1%) of caregivers reported often engagement in regular eHealth use. The most common eHealth service form caregivers used was the diabetes-related knowledge queries. Fig. 1 illustrates the information-seeking preferences and needs of caregivers when searching for eHealth information related to T1DM. Diet information was the most desired T1DM-related health information for caregivers of T1DM children, accounting for

Table 1
Demographic characteristics and eHealth-related preferences (N = 143).

Variable	Number	Percentage	Mean \pm SD
Age, years			37.2 \pm 4.7
Sex			
Male (father)	24	16.8%	
Female (mother)	119	83.2%	
Residence			
Rural	23	16.1%	
Urban	120	83.9%	
Education			
Elementary School	5	3.5%	
Junior School	32	22.4%	
High School	30	21.0%	
University and above	76	53.1%	
Family monthly income, yuan			
$\leq 10,000$	56	39.2%	
$> 10,000$	87	60.8%	
Age of children, years			8.8 \pm 3.1
Diabetes duration of children, years			2.7 \pm 2.3
Regular usage			
Smartphone	142	99.3%	
Computer	32	22.4%	
Tablet	22	15.4%	
Frequency of engage in eHealth use			
Seldom	25	17.5%	
Sometimes	32	22.4%	
Often	86	60.1%	
Types/forms of eHealth services preferences			
Diabetes related information/knowledge query	106	74%	
Peer communication/support	102	71.30%	
Health records or reminders	96	67.40%	
Health care services (online medical consultation)	54	37.60%	
Others	7	5.00%	

>90% (131/143, 91.7%). Their demands for information related to the latest progress in the treatment of T1DM, insulin injection, and exercise were 69.1% (99/143), 57.5% (82/143), and 52.5% (75/143) respectively. However, they had less demand for psychological and genetic-related information.

The relationship between scores of eHEALS and DRBS-P, ZBI

Table 2 shows the scores of eHEALS, DRBS-P, and ZBI of caregivers in this study (in SD units). Only 54 (37.76%) caregivers qualified by the eHEALS scale, with a total score of 30.07 ± 4.54 out of 40. The application dimension of network health information and services scored the highest, and the dimension of decision-making ability scored the lowest. The mean DBRS-P score was above the middle of the range at 0.67 (SD 0.14, scale range 0–1). Caregivers' mean ZBI score was 31.11 (SD 16.47, scale range 0–88), which indicates that caregivers have a mild-to-moderate burden of caring for their T1DM children. Of all the caregivers, 38 (26.57%) reported no burden, 62 (43.36%) reported mild-to-moderate burden, 43 (30.07%) reported high to severe burden.

Pearson's correlation coefficient to examine the relationship between diabetes management behavior (DRBS-P scores) and perceived caregiving burden (ZBI) and eHealth literacy of caregivers. The DRBS-P and the eHEALS were positively correlated ($r = 0.226$, $P = 0.007$, Fig. 2.). There was a negative correlation between ZBI and eHEALS scores ($r = -0.166$, $P = 0.047$, Fig. 3.).

Discussion

The main purpose of this study was to find out whether there is a potential relationship between the eHealth literacy of caregivers of children with T1DM and their disease management behaviors and its possible role in reducing the burden of caregivers, which has not been

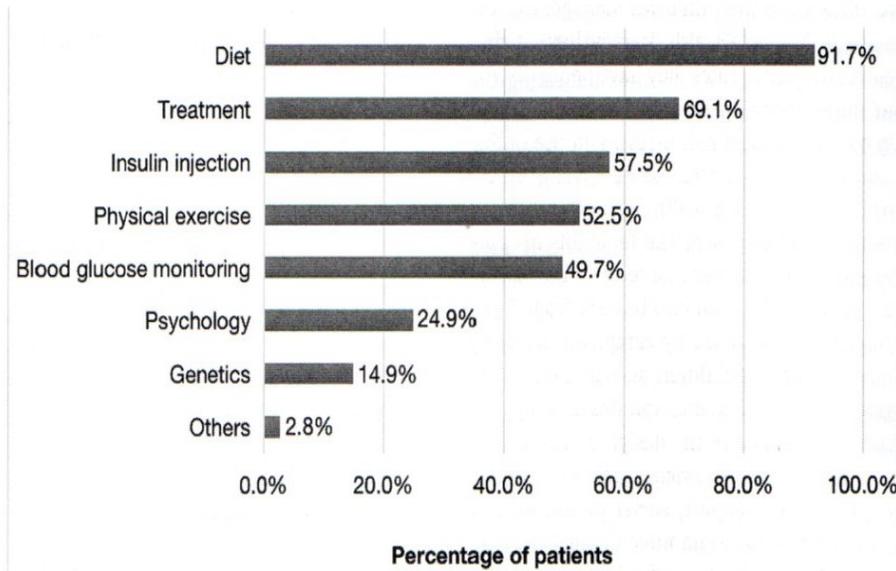


Fig. 1. Responses to “What aspects of information do you often look for on the Internet about T1DM?”.

Table 2
Scores of eHEALS, DRBS, and ZBI of the study subjects (N = 143).

Variable	Min	Max	Total
eHEALS scores	19	40	30.07 ± 4.54
application ability (average score)	2.2	5	3.78 ± 0.57
judgment ability (average score)	2.5	5	3.76 ± 0.64
decision-making ability (average score)	2	5	3.62 ± 0.72
DRBS-P scores	0.28	0.93	0.67 ± 0.14
ZBI scores	1	78	31.11 ± 16.47

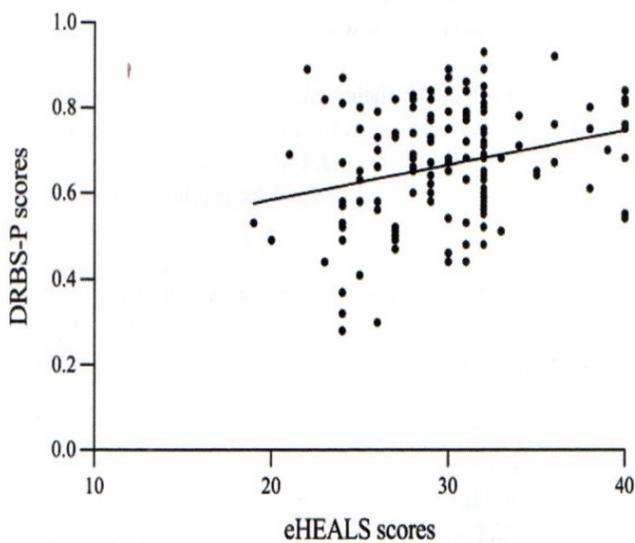


Fig. 2. The correlation between DRBS-P scores and the scores of eHEALS.

reported in previous studies. A positive correlation between DRBS-P scores and the scores of eHEALS and a negative correlation between ZBI and eHEALS scores was observed respectively in our study.

Previous studies on eHealth literacy in China were mainly conducted in healthy populations such as college students and the elderly, and most of the studies focused on exploring the current situation and influencing factors of eHealth literacy in different populations (Meng & Shen, 2018; Wang et al., 2022). Over time, researchers have discovered the importance of eHealth literacy in patients with chronic diseases, who may require more health-related resources or information than the generally healthy population (Cong et al., 2021; Zhang et al., 2021). And existing research shows that the influencing factors of eHealth literacy mainly include demographic characteristics (such as age, gender, income, etc.) (Zhang et al., 2023), attitudes (such as credibility perception of online health resources, etc.) (Shi et al., 2023), and motivations (such as health

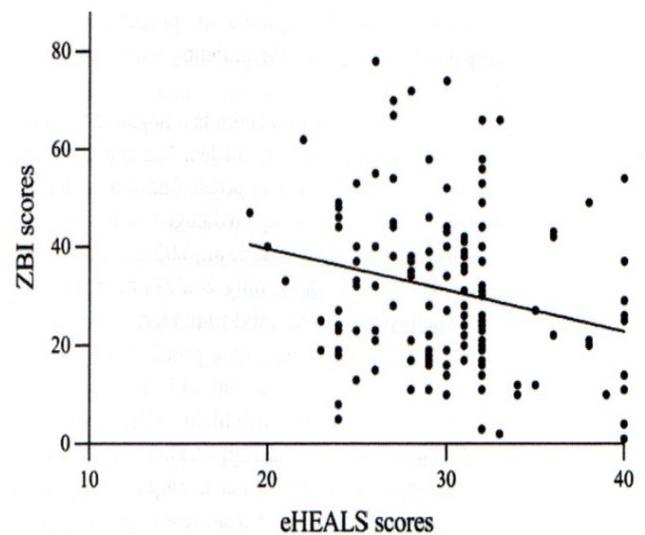


Fig. 3. The correlation between ZBI scores and the scores of eHEALS.

awareness and confidence in using Internet technology, etc.) (Xesfingi & Vozikis, 2016).

Instead of the widely discussed influencing factors, few studies have reported on users' specific eHealth-related preferences. As a result, medical staff may lack specificity in instructing different subjects to make full use of eHealth. Therefore, further understanding of caregivers' daily eHealth use preferences in this study may provide guidance for subsequent targeted interventions in the future. In our study, the majority of caregivers reported frequent engagement in eHealth uses (60.6% of caregivers answered often and 22.4% of caregivers answered always, respectively), and almost all caregivers (99.3%) tended to use mobile phones as eHealth use tools, suggesting that caregivers are important potential beneficiaries of eHealth. In the future, in order to reach more caregivers, interventions can be designed primarily on mobile phones, such as mobile applications. At the same time, we found that online medical consultation did not seem to be popular with caregivers of children with T1DM. This may be related to the fact that the development of telemedicine in China is still in its infancy, and this is an area that can be focused on and improved in the future.

In addition, some studies have gradually paid attention to the relationship between eHealth literacy levels and health-promoting behaviors (Do et al., 2020; Kim & Oh, 2021; Korkmaz Aslan et al., 2021; Yoğurtcu & Ozturk Haney, 2022). But these studies also tend to focus on healthy people. So far, there is still a relative lack of research on patients with chronic diseases or their main caregivers. On this basis, our study further clarified the positive correlation between eHealth literacy of

caregivers for children with T1DM and their diabetes management behaviors. That is, caregivers with higher eHealth literacy have higher diabetes behavior rating scores, which indicates they have better disease management behaviors. Individuals with different levels of eHealth literacy differ in their ability to find, understand, assess, and use online health information and address health-related issues (Wang et al., 2021). As a result, caregivers with higher eHealth literacy can obtain more disease-related information, and they have a better ability to apply the information to help them solve problems encountered in the disease management process (Kim et al., 2023). It can also be seen from Fig. 1 that most of the eHealth information searched by caregivers is closely related to the daily disease management of children, such as diet, insulin injection, exercise, blood glucose monitoring, etc. And this also suggests that these aspects should be strengthened in the design of T1DM education programs. Besides, various eHealth services, such as telemedicine, mobile health apps, game-based support, social platforms, and patient portals, are emerging as new ways to improve the management of T1DM (Duke et al., 2018), from which users with high eHealth literacy can benefit more. Kim et al. (2019) also found that caregivers' eHealth literacy also plays a crucial role in caring for cancer patients as family caregivers of cancer patients tend to seek and receive medical information concerning treatment options or procedures and are involved in making clinical decisions for patients, which is consistent with our findings.

At the same time, we also found that there is a negative correlation between eHealth literacy and caregiving burden. For caregivers, their burden mainly comes from psychological stress (emotional burdens), changes in parental roles and functions, challenges in daily management, and lack of social support (Kimbell et al., 2021; Saßmann et al., 2022; Tong et al., 2021). In this study, only 26.57% of caregivers reported no burden, 43.36% reported mild-to-moderate burden, and 30.07% reported high to severe burden. One possible reason for the differences in burden among caregivers is that with the rapid development of eHealth technology, caregivers with higher eHealth literacy are able to seek and utilize more solutions and approaches to address health problems and receive emotional support. For example, caregivers can get a lot of professional help and support from telemedicine (Eberle & Stichling, 2021). Electronic health technology can also assist caregivers with blood sugar monitoring and diet management, and so on (Schiaffini et al., 2016). At the same time, caregivers can also communicate with experienced peers through electronic social software for moral encouragement and support. Whitemore et al. (2020) reported that an eHealth program for parents of adolescents with T1DM improves parenting stress and is a good example of how eHealth can reduce the burden on caregivers.

At last, we have found that an increasing number of studies are attempting to provide eHealth interventions for people with diabetes or other chronic diseases in order to improve their disease management or health outcomes (Feigerlová et al., 2020; Hallensleben et al., 2019; Jackson et al., 2016; Janssen et al., 2017; Kemp & Velloza, 2018; Nkhoma et al., 2021). However, we have to mention that when adopting relevant intervention plans, researchers need to recognize that the basis of all eHealth-based interventions is that the research objects have a certain degree of eHealth literacy. Differences in the eHealth literacy of different subjects may lead to a certain bias in the study results, which should be noted. It is important that eHealth is developed in a way that takes all levels of health literacy and preference needs into account, with the goal of achieving a high range of user access.

Limitations

Our study has some limitations. First, although the study is a dual-center study, both centers in this study are from developed regions, which may limit the representativeness of the study population in some ways. Second, the results should be interpreted with caution, as this is a cross-sectional study, a causal relationship between caregiver eHealth

literacy and disease management behaviors and perceived caregiving burden cannot be established and should be explored longitudinally.

Implications to practice

This study further clarifies the correlation between T1DM caregivers' eHealth literacy level, diabetic behavior rating, and their caregiver burden, fully demonstrating that this population is a potential beneficiary of eHealth. It also suggests that in practice, hierarchical eHealth-based interventions should be designed according to the different levels of eHealth literacy of individuals, to enhance the ability of caregivers with different eHealth literacy level to fully utilize eHealth resources to improve their daily disease management skills and reduce their burden when caring for T1DM children.

Conclusions

In this study, we investigated the eHealth information seeking preferences of T1DM caregivers. In addition, the positive correlation between eHealth literacy and their diabetic behavior rating, as well as the negative correlation with the burden of care were observed. These findings should be taken into account for eHealth policy making and eHealth based interventions design and development.

Authors' contributions

J.Y., J.J.X. and Z.L. were responsible for the study design, and statistical analysis plans. Data analysis was primarily performed by J.Y. and reviewed by all coauthors. J.Y., Y.B.W, H.W. and M.J.Z. conducted the study and took responsibility for the authenticity of the data. J.Y. and Y. B.W. wrote the first draft of the article, which was reviewed by L.S. and Z.L. All authors have reviewed the final manuscript and approved the decision to submit for publication.

Declaration of Competing Interest

None declared.

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