Validation of the transactional eHealth literacy instrument with cancer caregivers☆

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ARTICLE INFO

ABSTRACT

Objective: Family members are important sources of support for patients with cancer. They access, evaluate, and engage with online information and discuss it with a cancer clinician. This study validates the 4-dimensions, 18-item Transactional eHealth Literacy Instrument (TeHLI) and proposed to include Clinical eHealth Literacy as a 5th dimension.
Methods: The Leukemia & Lymphoma Society (LLS) disseminated an online survey to 121 family member caregivers between March-June 2020. We conducted confirmatory factor analyses (1) to examine model fit for the 4-factor TeHLI in the cancer caregiver population, and (2) to examine the model fit when adding the 5th factor.
Results: The 4-dimension model yielded acceptable model fit (RMSEA = 0.09; 90% CI = 0.08-0.11; CFI = 0.98; TLI = 0.98; SRMR = 0.07). The 5-dimension model also yielded acceptable model fit (RMSEA = 0.08; 90% CI = 0.07-0.10; CFI = 0.97; TLI = 0.97; SRMR = 0.08), supporting the expansion of the TeHLI within this population.
Conclusion: The five-dimension TeHLI is a valid and reliable measure of eHealth literacy among blood cancer caregiver populations.
Innovation: The TeHLI can be used as an outcome measure for communication skills training for caregivers, patients, and clinicians.

1. Introduction

Family members play an integral role in an individual's healthcare experience, more significantly so when one receives a cancer diagnosis [1]. Receiving a cancer diagnosis is often unexpected and constitutes a substantial transition in a person's life, and family members often act as informal caregivers, providing critical support for patients and other family members [2]. One way that caregivers provide support is by acting as "surrogate seekers" [3] educating themselves about cancer through online health information seeking [4].

Caregivers who are informed by high-quality resources provide greater levels of positive support, enhance treatment compliance, and improve the overall continuity of care for the patient [5]. Online health information assists caregivers in accessing previously unavailable information pertinent to their family members' diagnosis and allows them to connect and learn from others' experiences with similar cancer care trajectories [6-8]. Caregivers also rely on scientific support more often than patients when it comes to evaluating the credibility of online health information, in that caregivers more frequently review citations provided on websites or research articles

to support their evaluation compared to patients [9]. As such, it can be hypothesized that there are unique differences in how patient and caregiver populations access, evaluate, and utilize information found online. Investigating how people access, understand, evaluate, and use online health information is imperative to promote family-centered, supportive communication in patients' healthcare management, particularly in blood cancer patient populations given the unique nature of this disease.

1.1. eHealth literacy and cancer caregivers

eHealth literacy is an intrapersonal skillset that is shaped by an individual's context, including their experiences and opportunities to seek online health information, including the availability of useful technologies [10]. According to the Transactional Model of eHealth Literacy (TMeHL), eHealth Literacy is defined as, "the ability to locate, understand, exchange, and evaluate health information from the Internet in the presence of dynamic contextual factors, and to apply the knowledge gained for the purposes of maintaining or improving health" [11]. Drawing from the Transactional Model of Communication [12], the TMeHL posits that

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eHealth literacy is a dynamic process that is continually adapted throughout an individual's engagement with the health care system, including health information seeking and decision-making conversations [13]. The TMeHL consists of three assumptions: (1) task- and user-oriented factors interact to produce physical, semantic, psychological, and physiological noise during the online experience; (2) eHealth literacy, a unique intrapersonal skill set, counteracts the effect of noise on this transaction; and (3) patient engagement that resulted from an interaction with online environments will influence future perceptions of eHealth usefulness, as well as the ability to effectively access, evaluate, communicate, and apply health information from these mediated environments [13]. eHealth literacy, as defined by the TMeHL, includes the following four competencies or skills: (1) functional (i.e., the ability to locate and understand online information); (2) communicative (i.e., the ability to exchange information between individuals within online contexts); (3) critical (i.e., the ability to appraise and evaluate the source and content of information found online); and (4) translational (i.e., the ability to use information learned from the Internet to inform healthcare decisions) [13].

In comparison to other Internet users, caregivers more frequently consult online reviews of clinicians and medical facilities and often access online information regarding drugs and medical treatments [14]. The ability for caregivers to effectively engage in these online information engagement behaviors is dependent on their eHealth literacy. A systematic review found that caregivers of adult care recipients have higher health literacy on average compared to patients [15]. Given their active engagement with online information, it is important to understand eHealth literacy in cancer caregiving populations, which would also be essential for tailoring eHealth literacy resources [16].

There are a multitude of instruments used to measure eHealth literacy [13]. The most widely cited instrument is the unidimensional eHealth Literacy Scale (eHEALS), which is the seminal measure published in 2006 [10]. Efthymiou and colleagues [17] argued the unique skillset needed for patients with dementia and their caregivers to engage with online health services in their adaptation of eHEALS for caregivers. Unfortunately, the eHEALS does not capture the communicative, interpersonal management competencies that are integral to the caregiver experience within online environments [18]. An instrument that measures these facets of caregiver eHealth literacy is imperative for two reasons. First, the data will help to inform interventions that improve online health information seeking and support-giving experiences. And, second, the data will allow scientists and clinicians to better understand how eHealth literacy interacts with the psychosocial factors that influence the caregiver experience.

1.2. The transactional eHealth literacy instrument

The Transactional eHealth Literacy Instrument (TeHLI) was developed to reflect the theoretical assumptions of the TMeHL [11]. Paige and colleagues [11] describe that the 4-factor, TeHLI was developed using a multi-stakeholder validation process, where eHealth experts and lay end-users from a community-engaged research program provided insight to the behavioral indicators captured by the items included in the instrument, as well as the word choice of each item to ensure that items were interpreted as they were intended. The internal structure of the instrument was later validated with a sample of individuals at-risk or living with Chronic Obstructive Pulmonary Disease (COPD). The results were positive, demonstrating good model fit with a 4-factor structure and strong evidence for external validity.

1.3. Clinical eHealth literacy

Caregivers frequently use online health information to inform healthcare decisions they discuss with clinicians during appointments [19]. This unique circumstance of discussing online health information during clinical interactions informed the need for the expansion of the 4-dimension TeHLI to encompass a 5th factor: Clinical eHealth Literacy.

We differentiate Clinical eHealth Literacy from Translational eHealth Literacy (one of the TeHLI original dimensions) as Translational eHealth literacy refers to a person's ability to apply health knowledge that was sought after and found online across diverse ecological contexts [11], whereas Clinical eHealth Literacy refers to the ability an individual has to discuss the online health information with a clinician. Speaking with a clinician should not be a *result* of eHealth literacy. Rather, talking to clinicians should be a central element of eHealth literacy that is intervened upon and considered in relation to corresponding skills (e.g., functional, communicative, critical, and translational). Although there are various reasons people do not discuss online health information with clinicians, one reason includes being concerned they could negatively impact their relationship with the clinician [20-22].

1.4. Research questions

The purpose of this study is to validate the TeHLI within a sample of caregivers of patients living with a blood cancer. Blood cancers require immediate clinical intervention soon after diagnosis, involving lengthy and possibly life-threatening treatments, prolonged in-patient hospitalizations, frequent visits to the emergency department, and complex side effects [23-25]. The sudden onset of intense treatment regimens related to blood cancer drastically disrupts the family system [26] and often requires a family member to immediately take on the primary caregiver role of the diagnosed patient [27].

Since the factors that typically determine a person's eHealth literacy have not been extensively examined in caregiver populations [28] and given the significant amount of support caregivers provide to cancer patients [4,29], it is important to validate the utility of the TeHLI in caregiver populations independently.

- RQ1: What evidence exists for the internal structure and reliability of the 4-dimension TeHLI among a cancer caregiver population?
- RQ2: What evidence exists to support adding a 5th dimension (i.e., Clinical eHealth literacy) to the TeHLI in a cancer caregiver population?

2. Methods

2.1. Participants

The authors of this study partnered with The Leukemia & Lymphoma Society (LLS), a 501 charitable organization that aims to improve the quality of life of individuals with blood cancer and their families, in an ongoing cooperative effort to conduct communication-focused research that supports those diagnosed with a blood cancer. The second and third authors have had a collaboration with LLS for several years [26].

Through this partnership, LLS recruited caregivers to complete an online survey. Authors were blinded to any identifiable information collected by LLS. Recruitment materials were developed by the second and third authors, which were then sent to caregivers through LLS' constituent database.

Caregivers were able to complete the survey between March 30 and June 1, 2020. Recruitment advertisements for the study included direct emails from LLS staff to the LLS's constituent database and a post that invited members of LLS's online community site for patients and caregivers. LLS sent members two reminders after the first invitation. Caregivers who participated in this study met specific eligibility criteria: (a) at least 18 years old and (b) caring for a living parent, stepparent, or parent-in-law with a blood cancer who was still in treatment or had finished treatment less than one year from the time the survey was completed. Each caregiver received $25 in compensation for participation in the survey. We received institutional review board approval from the University of Florida (#IRB201902191).

2.2. Measures

The survey took approximately 20 minutes to complete and had questions to examine caregivers' parent-child communication as well as clinical communication, specifically within the context of caring for a parent diagnosed with a blood cancer. For this analysis, we focus on the eHealth literacy measure as well as demographic questions.

We measured eHealth literacy with Paige and colleagues' Transactional eHealth Literacy Instrument (TeHLI) [13]. The TeHLI contains four dimensions consistent with the TMeHL, which were developed from rigorous instrument development and testing procedures [13]. The multi-dimensional instrument includes 18-items using a 5-point Likert-type scale, where 1 = strongly disagree and 5 = strongly agree. The four competencies this measure includes are: (1) Functional (e.g., "I can summarize basic health information from the Internet in my own words."); (2) Communicative (e.g., "I have the skills I need to talk about health topics on the Internet with multiple users at the same time."); (3) Critical (e.g., I can tell when health information on the Internet is fake."); and (4) Translational (e.g., "I can use the Internet as a tool to improve my health.").

We expanded the TeHLI to include a Clinical eHealth literacy subscale. The additional subscale includes five items, all anchored on the same 5-point Likert scale as other items in the TeHLI. Items from this subscale were drafted among two members of the research team who have a strong publication record in eHealth literacy and patient-clinician communication about online health information. The items were shared with other team members for purposes of clarification and face validity. The items include: (1) I know how to talk with my [parent, step-parent, or parent-in-law's] doctor about health information that I find on the Internet; (2) I know how to talk with my [parent, step-parent, or parent-in-law's] doctor about medical advice that I find on the Internet; (3) I can ask my [parent, step-parent, or parent-in-law's] doctor for health information resources on the Internet; (4) I can ask my [parent, step-parent, or parent-in-law's] doctor if health information I find on the Internet is relevant to my [parent, step-parent, or parent-in-law's] situation; and (5) I can ask my [parent, step-parent, or parent-in-law's] doctor if health information I find on the Internet is accurate.

2.3. Data analysis

We used SPSS v27 to conduct frequency and descriptive statistics to describe the sample. We also conducted descriptive statistics to describe the central tendency statistics for each eHealth literacy dimension and overall score. To answer RQ1, we used Mplus 8.6v to conduct a confirmatory factor analysis (CFA) to examine model fit for the original 4-factor TeHLI. To answer RQ2, a second CFA was conducted to examine model fit when adding a 5th factor (i.e., Clinical eHealth Literacy). Model fit indices in each CFA were used to establish "good fit" [30]: Root Mean Square of Error Approximation (RMSEA) value less than or equal to .08, a statistically non-significant ($p > .05$) chi-squared value, Comparative Fit Index/Tucker-Lewis Index (CFI/TLI) values greater than.90, and a Squared Root Mean Residual (SRMR) value with average residual correlations $\leq .08$. R^2 estimates for items in the model should be above 0.50. We also examined whether standardized factors loadings for each dimension were statistically significant ($p < .05$). Reliability estimates were deemed acceptable if Cronbach's α were $\geq .70$.

3. Results

3.1. Sample characteristics

Table 1 shows the socio-demographics of the sample. Caregivers were, on average, 44.37 years old (SD = 11.48 years). Approximately 71% identified as white and 16% identified as Hispanic. Over half (55%) of caregivers had earned at least a bachelor's degree and 60% were employed on a full-time basis. Despite being full-time employees, over 25% reported providing all care to patients whereas an equal proportion provided some

Table 1
Socio-demographic characteristics of the sample, N = 121.

Variable	
Age, M (SD)	44.37 (11.48)
Sex, n (%)	
Male	21 (18.9)
Female	88 (79.30)
Other	2 (1.80)
Missing	10 (8.30)
Race, n (%)	
White	87 (71.90)
Non-White	22 (18.20)
Missing	12 (9.90)
Ethnicity, n (%)	
Non-Hispanic or Latino	92 (76.0)
Hispanic or Latino	19 (15.70)
Missing	10 (8.30)
Education, n (%)	
Bachelor's degree and lower	67 (55.40)
Master's degree and higher	44 (36.40)
Missing	10 (8.30)
Employment Status, n (%)	
Employed Full-Time	73 (60.30)
Employed Part-Time	8 (6.60)
Self-Employed	6 (5.0)
Not Employed	14 (11.60)
Retired	10 (8.30)
Missing	10 (8.30)
Amount of Care Provided to Patient, n (%)	
A little	8 (6.60)
Some	40 (33.10)
Most	40 (33.10)
All	33 (27.3)
Frequency of Attending Healthcare Visits with Patients, n (%)	
Never	5 (4.10)
Sometimes	21 (17.40)
About half the time	13 (10.70)
Most of the time	31 (25.60)
Always	47 (38.80)
Missing	4 (3.30)

(33%) or most (33%) of the care. Over half of the caregivers attended healthcare visits with patients most of the time (25.60%) or always (38.80%). The vast majority (88%) had searched for health information on the Internet in the past and over half (57%) said they talked to the patient's doctor about health information from the Internet. Caregivers commonly cared for patients with leukemia (n = 49; 40.50%), myeloma (n = 29; 24.0%), or lymphoma (n = 28; 23.10%).

3.2. eHealth Literacy

Table 2 includes the following for each dimension of TeHLI. We also captured these statistics for a 5th dimension, Clinical eHealth Literacy. Based on a 5-point Likert-type scale, participants reported above average eHealth literacy scores across all five competencies. Caregivers reported the highest level of "agreement" for *Functional eHealth literacy*, which indicated they have the skills necessary to successfully access and understand online health information. They also "agreed" they could apply what they learn online to their patient's health situation (*Translational eHealth literacy*) and are able to discuss this information with the patient's healthcare team during clinical encounters (*Clinical eHealth literacy*). Caregivers, although

Table 2
eHealth literacy scores.

eHealth Literacy Dimension	M (SD)	Range	Alpha
Functional	4.43 (.60)	2.50	0.87
Communicative	3.85 (.91)	3.75	0.87
Critical	3.78 (.92)	3.60	0.92
Translational	4.10 (.71)	3.00	0.87
Clinical	4.16 (.68)	3.00	0.87

trending toward higher scores, neither agreed nor disagreed that they have the skills to effectively exchange (*Communicative eHealth literacy*) and evaluate (*Critical eHealth literacy*) online health information pertaining to the patient's blood cancer.

3.3. TeHLI Scores

As shown in Table 3, the 4-factor a priori measurement model guided by the TeHLI yielded acceptable model fit (RMSEA = 0.09; 90% CI = 0.08-0.11; CFI = 0.98; TLI = 0.98; SRMR = 0.07). Statistically significant standardized factor loadings were identified for each dimension: Functional (lambda = 0.83-0.94; $p < .001$), Communicative (lambda = 0.78-0.92; $p < .001$), Critical (lambda = 0.88-0.90; $p < .001$), and Translational (lambda = 0.81-0.93; $p < .001$). Table 4 shows that data produced by the 4-factors of the TeHLI had a moderate to high positive association with one another (r = .53 to .72, $p < .001$).

3.4. TeHLI + Clinical eHealth Literacy

Also, shown in Table 3, the 5-factor a priori measurement model guided by the TeHLI yielded acceptable model fit (RMSEA = 0.08; 90% CI = 0.07-0.10; CFI = 0.97; TLI = 0.97; SRMR = 0.08). Statistically significant standardized factor loadings were identified for each eHealth literacy dimension: Functional (lambda = 0.80-0.93; $p < .001$), Communicative (lambda = 0.76-0.90; $p < .001$), Critical (lambda = 0.86-0.90; $p < .001$), and Translational (lambda = 0.82-0.92; $p < .001$), and Clinical (lambda = 0.78-0.92; $p < .001$). Table 4 also shows that data produced by the Clinical eHealth Literacy subscale resulted in a moderate-to-strong correlation with each of the 4-factors in TeHLI (r = .35 to .48, $p < .001$). Variance (R^2) estimates for all items in the instrument were above the recommended threshold: Functional (0.64 to 0.87), Communicative (0.59 to 0.81), Critical (0.74 to 0.81), Translational (0.67 to 0.83), and Clinical (0.61 to 0.85).

4. Discussion and conclusion

4.1. Discussion

The purpose of this study was to validate the TeHLI instrument among caregivers of patients with a blood cancer and to examine the evidence to support adding Clinical eHealth Literacy as a fifth dimension of TeHLI. Findings of this study demonstrate that the TeHLI is a valid and reliable instrument to measure eHealth literacy among caregivers of patients with blood cancer. To support the translation of independent online health information seeking among patients into healthcare consultations with clinicians, the results of this study also support adding Clinical eHealth Literacy as a fifth dimension. The additional dimension is intended to understand cancer caregivers' perceived skills in talking with clinicians about health information from the Internet.

Data collected with the TeHLI among caregivers of patients diagnosed with a blood cancer resulted in good model fit. Model fit is consistent with data produced in the seminal validation study using the TeHLI [11].

Table 3
Model fit statistics for TeHLI

	TeHLI	TeHLI + Clinical eHealth Literacy
Chi-Squared (X^2)		
Value	256.09	356.69
Degrees of freedom (df)	130	221
P-value	$P < .001$	$P < .001$
RMSEA	0.09	0.08
90% CI	0.08-0.11	0.07-0.10
CFI	0.98	0.97
TLI	0.98	0.97
SRMR	0.07	0.08

Note. Root Mean Square Approximation (RMSEA); Comparative Fit Index (CFI); Tucker-Lewis Index (TLI); Standardized Root Mean Squared (SRMR)

Table 4
Correlation of eHealth literacy scores

eHealth Literacy Dimension	1	2	3	4	5
Functional (1)	–				
Communicative (2)	0.66***	–			
Critical (3)	0.53***	0.72***	–		
Translational (4)	0.56***	0.62***	0.69***	–	
Clinical (5)	0.48***	0.46***	0.40***	0.35***	–

*** $p<0.001$.

This validation supports scholarship that characterizes the vital role caregivers play in cancer patients' healthcare management, which includes providing informational support and seeking online information to inform their loved one's care [26,31,32]. Properly understanding caregiver eHealth literacy skills is particularly important for blood cancer patient caregivers due to the often-immediate onset of treatment required for patients with blood cancer and need for more long-term care, including both emotional and informational support.

Additionally, results of this study support incorporating the Clinical eHealth Literacy scale into the TeHLI measurement model in cancer caregivers. Data produced by each of the 4 TeHLI subscales are moderately-to-strongly correlated with the new, Clinical eHealth Literacy subscale. Translational and Clinical eHealth literacy had a moderately strong, positive correlation suggesting that these scales measure two inherently different but related behaviors.

The data used to complete this scale validation procedure were collected as part of a cross-sectional online survey to aid in the development of resources and interventions for caregivers of a parent diagnosed with a blood cancer. eHealth literacy is a unique skill set that develops across one's lifespan, which makes establishing larger, more generalizable effects more difficult with cross-sectional datasets. Surveillance efforts are needed to monitor eHealth literacy over a period of time in this population, including future research that aims to test the test-retest reliability of the TeHLI.

Family cancer caregivers' eHealth literacy can vary given various psychosocial or cultural factors as well as disease contexts [13,17,33]. This study solely aimed to provide evidence for the internal structure of the TeHLI and its expansion (i.e., TeHLI-C) within this population. Future research is needed to explore whether data produced by TeHLI remain stable, regardless of different psychosocial factors and phenomena that are associated with eHealth literacy (e.g., age, socioeconomic status, race/ethnicity) [34]. Measurement invariance ensures that the construct(s) being captured by a data collection instrument function similarly across pre-specified groups, and that any differences detected between two groups are due to a real difference and not a function of external factors [35].

As this study examined constructs taken from a larger data set, those caring for a patient diagnosed with a blood cancer were the only cancer patient/caregiver population surveyed originally. Future studies should test the five-dimension TeHLI with other cancer diagnoses to ensure its validity across disease contexts. The study participants were also highly educated, with over 90% having attended university. Due to their education level, this sample was more likely to have higher levels of health literacy. The caregivers included in this study were also younger on average, with caregiving responsibilities focused solely for their parents. Future studies would benefit from including different types of dyads of caregivers and patients (i.e., spousal dyads, older age demographic) to assess these additional contextual factors influencing eHealth literacy. Finally, the study yielded a small sample size of 121 participants. Future research should not only aim to incorporate a wider range of participants with various demographics (e.g., education level, age, type of caregiving dyad) but should recruit a more sufficient sample of caregivers to expand our understanding of caregiver eHealth literacy.

4.2. Innovation

The TeHLI is a 4-factor, 18-item instrument that measures self-reported eHealth literacy. Adding a Clinical eHealth Literacy as a fifth dimension and

evaluating its model fit within the larger TeHLI is innovative for a variety of reasons. One of the primary reasons is the ability to identify and screen caregivers who have the skills to use online health information but have less developed skills to speak with a clinician about what they have found. Previous work has demonstrated cancer caregivers access and evaluate the credibility of online health information differently than patients [9]. The addition of the Clinical eHealth Literacy dimension serves an essential function in determining how caregivers apply and discuss this online health information in clinical encounters, if at all.

The validation and expansion of TeHLI among cancer caregivers also provides a deepened understanding of the caregiving experience and aids in the development of translational health and family communication interventions to enhance patient care, not only for the patient but for their broader family system. Identifying the gaps in caregivers' translation and application of eHealth literacy skills into various clinical encounters will help provide researchers a more nuanced knowledge of what areas of eHealth literacy need to be addressed to ensure communication skills training programs are being developed and implemented in meaningful ways.

The TeHLI-C instrument holds important implications for both research and clinical practice. Examining caregivers' eHealth literacy allows researchers and clinicians to assess their baseline capacity to understand, access, evaluate, and communicate about online health information to support family members' health behaviors and outcomes. A tangible next step for future research could include audio/video recording clinical interactions of caregivers with varying levels of eHealth literacy and scoring their capacity to discuss health information from the Internet with a clinician. An additional way to validate the TeHLI-C could include an assessment to determine if this new 5-dimension eHealth literacy scale predicts whether individuals speak to a clinician about health information found online.

eHealth Literacy is integral to identify and understand, in caregiver populations especially, because caregivers are often the arbiters of information within the family system. Caregivers not only search for information and evaluate its credibility pertaining to their family member's condition, but they also present this information during clinical encounters and actively participate in healthcare decision making. Determining caregivers' level of comfort and ability to bring up and discuss information with clinicians is important to tailor future patient-provider communication interventions and develop unique triadic communication skills programs that accurately address competencies cancer caregivers should enact across the disease trajectory.

4.3. Conclusion

Caregivers are a vital, yet critically understudied population of a patient's healthcare team. Results of this study have important theoretical and practical implications for expanding the scope and utility of the TeHLI for both patient and caregiver populations, ultimately informing future dyadic and triadic communication interventions for patients and their caregivers, family members, and clinicians. Further research is needed to validate the efficacy of the TeHLI in caregiver populations outside of caregivers of patients with a blood cancer to develop a better understanding how this model applies in this essential group for the enhancement of patients' care.

Declaration of Competing Interest

The authors do not have any conflict of interest to report for this manuscript submission.

References

[1] Woźniak K, Iżycki D. Cancer: a family at risk. pm. 2014;4:253–61. https://doi.org/10.5114/pm.2014.45002.
[2] Given BA, Given CW, Kozachik S. Family Support in Advanced Cancer. CA: A Cancer Journal for Clinicians. 2001;51(4):213–31. https://doi.org/10.3322/canjclin.51.4.213.
[3] Cutrona SL, Mazor KM, Vieux SN, Luger TM, Volkman JE, Finney Rutten LJ. Health information-seeking on behalf of others: characteristics of "surrogate seekers". J Canc Educ. 2015;30(1):12–9. https://doi.org/10.1007/s13187-014-0701-3.
[4] Berland GK, Elliott MN, Morales LS, et al. Health Information on the Internet: Accessibility, Quality, and Readability in English and Spanish. JAMA. 2001;285(20):2612. https://doi.org/10.1001/jama.285.20.2612.
[5] Glajchen M. The emerging role and needs of family caregivers in cancer care. J Support Oncol. 2004;2(2):145–55.
[6] Maddock C, Lewis I, Kafait A. 3643 POSTER European Patient Online Information Needs. European Journal of Cancer. 2011;47:S271–2. https://doi.org/10.1016/S0959-8049(11)71240-0.
[7] Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? Social Science & Medicine. 2007;64(9):1853–62. https://doi.org/10.1016/j.socscimed.2007.01.012.
[8] Chen S, chuan.. Information needs and information sources of family caregivers of cancer patients. Aslib Journal of Information Management. 2014;66(6):623–39. https://doi.org/10.1108/AJIM-08-2013-0075.
[9] Vasquez TS, Bylund CL, Alpert J, et al. Comparing transactional eHealth literacy of individuals with cancer and surrogate information seekers: A Mixed Methods Study. JMIR Formative Research. 2022. In press.
[10] Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res. 2006;8(2):e9. https://doi.org/10.2196/jmir.8.2.e9.
[11] Paige SR, Stellefson M, Krieger JL, Miller MD, Cheong J, Anderson-Lewis C. Transactional eHealth Literacy: Developing and Testing a Multi-Dimensional Instrument. Journal of Health Communication. 2019;24(10):737–48. https://doi.org/10.1080/10810730.2019.1666940.
[12] Barnlund D. The context of change. In: Sereno K, Mortensen C, editors. Foundations of Communication Theory. Harper & Row; 1970. p. 83–102.
[13] Paige SR, Stellefson M, Krieger JL, Anderson-Lewis C, Cheong J, Stopka C. Proposing a Transactional Model of eHealth Literacy: Concept Analysis. J Med Internet Res. 2018;20(10):e10175. https://doi.org/10.2196/10175.
[14] How online family caregivers interact with their health online. Pew Research Center: Internet, Science & Tech.; 2013 Published online. https://www.pewresearch.org/internet/2013/06/20/how-online-family-caregivers-interact-with-their-health-online/.
[15] Yuen EYN, Knight T, Ricciardelli LA, Burney S. Health literacy of caregivers of adult care recipients: A systematic scoping review. Health Soc Care Community. 2018;26(2). https://doi.org/10.1111/hsc.12368.
[16] Fennell G. Marketing and promoting carer education Published online. ; 2007. (Unpublished manuscript).
[17] Efthymiou A, Middleton N, Charalambous A, Papastavrou E. Adapting the eHealth Literacy Scale for Carers of People With Chronic Diseases (eHeals-Carer) in a Sample of Greek and Cypriot Carers of People With Dementia: Reliability and Validation Study. J Med Internet Res. 2019;21(11):e12504. https://doi.org/10.2196/12504.
[18] Norman C. eHealth Literacy 2.0: Problems and Opportunities With an Evolving Concept. J Med Internet Res. 2011;13(4):e125. https://doi.org/10.2196/jmir.2035.
[19] Wolff JL, Guan Y, Boyd CM, et al. Examining the context and helpfulness of family companion contributions to older adults' primary care visits. Patient Education and Counseling. 2017;100(3):487–94. https://doi.org/10.1016/j.pec.2016.10.022.
[20] Chiu YC. Probing, Impelling, But Not Offending Doctors: The Role of the Internet as an Information Source for Patients' Interactions With Doctors. Qual Health Res. 2011;21(12):1658–66. https://doi.org/10.1177/1049732311417455.
[21] Imes RS, Bylund CL, Sabee CM, Routsong TR, Sanford AA. Patients' Reasons for Refraining from Discussing Internet Health Information with Their Healthcare Providers. Health Communication. 2008;23(6):538–47. https://doi.org/10.1080/10410230802460580.
[22] Bylund CL, Gueguen JA, D'Agostino TA, Imes RS, Sonet E. Cancer patients' decisions about discussing Internet information with their doctors. Psycho-Oncology. 2009;18(11):1139–46. https://doi.org/10.1002/pon.1511.
[23] Bertero C, Eriksson BE, Ek AC. Explaining different profiles in quality of life experiences in acute and chronic leukemia. CANCER NURSING. 1997;20(2):100–4. https://doi.org/10.1097/00002820-199704000-00004.
[24] Berterö C, Eriksson BE, Ek AC. A substantive theory of quality of life of adults with chronic leukaemia. International Journal of Nursing Studies. 1997;34(1):9–16. https://doi.org/10.1016/S0020-7489(96)00025-9.
[25] Bryant AL, Deal AM, Walton A, Wood WA, Muss H, Mayer DK. Use of ED and hospital services for patients with acute leukemia after induction therapy: One year follow-up.

Leukemia Research. 2015;39(4):406–10. https://doi.org/10.1016/j.leukres.2015.01.006.

[26] Fisher CL, Mullis MD, Kastrinos A, et al. "Home wasn't really home anymore": Understanding caregivers' perspectives of the impact of blood cancer caregiving on the family system. Support Care Cancer. 2021;29(6):3069–76. https://doi.org/10.1007/s00520-020-05811-4.

[27] Pailler ME, Johnson TM, Kuszczak S, et al. Adjustment to Acute Leukemia: The Impact of Social Support and Marital Satisfaction on Distress and Quality of Life Among Newly Diagnosed Patients and Their Caregivers. J Clin Psychol Med Settings. 2016;23(3):298–309. https://doi.org/10.1007/s10880-016-9459-6.

[28] Moore C, Hassett D, Dunne S. Health literacy in cancer caregivers: a systematic review. J Cancer Surviv. 2021;15(6):825–36. https://doi.org/10.1007/s11764-020-00975-8.

[29] Dionne-Odom JN, Currie ER, Johnston EE, Rosenberg AR. Supporting Family Caregivers of Adult and Pediatric Persons with Leukemia. Seminars in Oncology Nursing. 2019;35(6):150954. https://doi.org/10.1016/j.soncn.2019.150954.

[30] Hu YY. Physicians' Needs in Coping With Emotional Stressors: The Case for Peer Support. Arch Surg. 2012;147(3):212. https://doi.org/10.1001/archsurg.2011.312.

[31] Repetto L, Piselli P, Raffaele M, Locatelli C. Communicating cancer diagnosis and prognosis: When the target is the elderly patient-a GIOGer study. European Journal of Cancer. 2009;45(3):374–83. https://doi.org/10.1016/j.ejca.2008.08.020.

[32] Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Attitudes and experiences of family involvement in cancer consultations: a qualitative exploration of patient and family member perspectives. Support Care Cancer. 2016;24(10):4131–40. https://doi.org/10.1007/s00520-016-3237-8.

[33] Song L, Tatum K, Green G, Chen R. eHealth Literacy and Partner Involvement in Treatment Decision Making for Men With Newly Diagnosed Localized Prostate Cancer. Oncology Nursing Forum. 2017;44(2):225–33. https://doi.org/10.1011/17.ONF.225-233.

[34] Tennant B, Stellefson M, Dodd V, et al. eHealth Literacy and Web 2.0 Health Information Seeking Behaviors Among Baby Boomers and Older Adults. J Med Internet Res. 2015;17(3):e70. https://doi.org/10.2196/jmir.3992.

[35] Paige SR, Miller MD, Krieger JL, Stellefson M, Cheong J. Electronic Health Literacy Across the Lifespan: Measurement Invariance Study. J Med Internet Res. 2018;20(7):e10434. https://doi.org/10.2196/10434.