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Review

Understanding the impact of family caregiver cancer literacy on patient health outcomes

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Abstract

Objective: Family caregivers play a significant role in the diagnosis, treatment, and recovery of individuals with cancer. This position paper reviews and links the research on family caregiving and health information with the importance of cancer literacy.


Results: Family members are important sources of health information, informal caregivers who learn and enact medical procedures, and influential aspects of patients’ healthcare and treatment decision-making, but are not seriously considered by healthcare practitioners or researchers in terms of assessing and improving health literacy. Further, very few studies have directly examined or acknowledged the potential importance of family caregiver health literacy.

Conclusion: The extent to which family caregivers can comprehend the health information they receive along with the patient is crucial for the patient to achieve the most successful health outcome.

Practice implications: To acknowledge the impact that family caregiver health literacy could have on patient health outcomes, targeted practical recommendations for understanding family caregiver health literacy in the cancer context are proposed: (1) family member health literacy should be assessed; (2) close relational partners should be trained as peer health educators; (3) written cancer information should be provided directly to family caregivers; (4) health interactions between family caregivers and patients should be improved; (5) theoretical perspectives into the understanding of family caregiver health literacy should be integrated into practice; and (6) patient and family caregiver health literacy should be improved.

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Well, when the doctor gave us the news, you know, about my husband’s lung cancer, we were both stunned. It took us a good while, a few days, really, before we could really start to process what this meant, or might mean, and... well... (long pause)—Agnes, 54, wife of cancer survivor

Research consistently highlights the vital importance that health literacy plays in individuals’ negotiation of the healthcare process. Health literacy involves “the evolving skills and competencies needed to find, comprehend, evaluate, and use health information and concepts to make educated choices, reduce health risks, and improve quality of life” (1: p. 119). Going beyond basic literacy skills, health literate individuals must apply health terms and knowledge to novel circumstances and take part in conversations regarding medicine, health, scientific knowledge, and culture [1]. Inadequate health literacy skills are linked to patient misunderstanding of essential health information and low rates of compliance with physician recommendations [2].

When considered in the context of a serious illness such as cancer, health literacy takes on particular importance and those with low health literacy can be vulnerable to cancer health disparities. Namely, being unable to comprehend or understand information related to preventative cancer procedures could delay an individual’s cancer diagnosis [3,4]. Individuals with lower health literacy, however, are more influenced by their...
support networks to seek screening [3]. However, network members can also be considered a vulnerable audience, as they often do not have sufficient access to the patients’ health information and may also not be health literate, and thus may not provide accurate or useful information to the patient.

Even though they play a significant role in all aspects of care provision [3], third party influence on patient care and health outcomes has not been a primary concern of health literacy researchers. The family caregiver literature overwhelmingly indicates that close family members who care for patients receive information from healthcare providers, provide patient information to physicians, aid in treating and caring for the patient, and weigh in on treatment decisions. Each of these important caregiving dimensions can surely be impeded by inadequate family caregiver health literacy. As such, it is crucial to understand all aspects of both patients’ and family caregivers’ health literacy. This position paper thus offers an overview of literature that examines the importance of family caregivers in cancer treatment and outcomes from the perspective of health literacy as well as targeted recommendations for including the family caregiver in treatment protocols and research on health literacy in the cancer context. The overarching goal is to initially gain insight into the importance of family caregivers’ health literacy and its role in cancer care in hopes of encouraging researchers to recognize the potential significance of family caregiver health literacy levels in terms of cancer outcomes.

1. The family caregiver

Because humans are social creatures, we experience the events of our lives within a web of relationships. When these events are potentially life threatening, such as a cancer diagnosis, we are even more likely to turn to our support network for help. Research conducted by a wide range of disciplines over a variety of life challenges consistently finds that people cope better when they report having a strong support network [10–12]. Although any number of close relational partners can care for an individual who is diagnosed with cancer, the family role in caregiving and social support provision during a cancer crisis is of primary interest in this position paper.

The family is an interpersonal “context with the most immediate effects on disease management and with the greatest implications for intervention” (5: p. 8). Further, the family setting is where most disease management occurs [5]. Indeed, as cancer patients and their families know, “cancer is a disease of the family rather than of an individual” (6: p. 157). Any serious health diagnosis, especially one regarding cancer, impacts the entire family network in a myriad of ways [7]. As such, family members play substantial psychological and biomedical roles in cancer patient care and subsequent health outcomes [5]. Specifically, families serve as a “constant support system” to the cancer patient (8: p. 8), and both observe and actively participate in the patient’s care [9].

Family caregivers are defined as unpaid individual family members who aid in patients’ physical care and disease process coping [13]. This aid, typically referred to as social support, covers three dimensions: informational, instrumental, and emotional. Informational support involves sharing knowledge about a problem or issue and, thus, is most directly related to health literacy. Provision of this type of support helps the cancer patient to access, process, and act upon the health-related information that he or she is receiving. Instrumental support is related to tasks. Provision of this type of support includes such behaviors as driving the cancer patient to a doctor’s appointment, preparing meals, and cleaning the house. Emotional support is directly tied to coping with fear and the unknown. Provision of this type of support helps the cancer patient to feel valued, cared for, and loved.

The amount of social support provided by families is inestimable. There are approximately 15 million family caregivers in the United States [14]. Further, the average duration of caregiving for clinic cancer patients is approximately 29 months [13]. Of particular interest to the topic of cancer health literacy is how family caregivers manage information related to the patient’s illness.

1.1. Family caregivers and health information

Healthcare professionals recognize that patients need health information, but are less likely to realize that the families also have information needs. Families want to be involved in health-related decision-making, but they also require health-related information to provide adequate and appropriate support to the cancer patient [7]. Family caregivers provide more hands-on, day-to-day care than do any other individuals and need not only access to information, but also the ability to process and act upon that information in order to provide the best quality care.

Family caregivers fulfill a wide range of functions from exchanging information among all parties; interpreting language; offering additional viewpoints, explanations, and interpretations of medical diagnoses; collaborating to offer personal care to the patient and learning technical procedures; taking part in therapeutic regimens; and, encouraging patients to comply with their medical treatments [15–18]. Despite this, family caregivers often battle for healthcare providers’ respect and to be treated as a full partner in the patient’s care [17].

In the specific context of cancer care, the family caregiver and how he/she manages information takes on a particularly significant role. Beach and Good [19] describe the importance of the family caregiver when treating a cancer patient:

As laypersons, family members can exhibit a remarkable ability to learn technical/medical information. Terms, applications, and explanations about how the body functions and is impacted by an illness are invoked during condensed and over extended periods. Such information may not be ‘technically correct,’ at least by medical experts’ standards, but is nonetheless utilized when attempting to understand and discern the appropriateness, and potential consequences, of diagnosis and treatment options. (p. 17)

Family caregiving is thus particularly notable in three aspects of cancer prevention and treatment: (a) preventative
screenings such as mammograms, (b) caregiving behaviors upon diagnosis, including information management and aid in medical decision-making, and (c) interacting with healthcare providers to best treat the patient. Each of these aspects of cancer communication, in turn, involves sufficient levels of health literacy.

In terms of prevention, family plays a significant role in encouraging healthy behaviors in general [7]. When an individual experiences symptoms, he or she usually turns first to a loved one who then encourages the individual to seek medical advice [20–22]. Even without symptoms, individuals report a greater likelihood of undergoing screening procedures when recommended by a family member. Almost one-third of women indicate that they would be likely to get a mammogram if a relative recommended it [3].

Once diagnosed, a caregiver’s role is central in the patient’s treatment of and long-term adaptation to cancer [23]. Many individuals diagnosed with cancer are overwhelmed by the amount and complexity of required decisions [24]. Upon diagnosis, patients employ multiple health information sources, including friends, family, and knowledgeable acquaintances, with family and friends being the most important sources [22,25]. This is particularly true for low-income patients, a group who traditionally struggles with health literacy [26].

Cancer patients and their family members actively seek out individuals who have some sort of medical expertise, whether through formal training or prior cancer experience. Interviews conducted by the second author reveal that cancer patients and their primary family caregivers repeatedly report turning to relatives and friends who are nurses, pharmacists, or other kinds of health professionals to help them access and process the abundant information that they have accumulated. In addition, they turn to individuals who have already experienced cancer to learn more from their first hand accounts. While these cancer survivors can provide valuable information that can only come from personal experience, the information they have may be inappropriate or inaccurate. If this individual has a different kind of cancer, the information may not be relevant to this second case. Even when the diagnosis is the same, if this individual was diagnosed and treated more than 5 years ago, treatment protocols may have changed dramatically. If the current cancer patient and the cancer survivor do not carefully assess these issues, the information may do more harm than good. Those with low health literacy may either be more predisposed to turn to their personal network in order to process information or may be less inclined for fear of being “found out” as struggling to understand health-related information. While individuals trust these interpersonal information sources because they are motivated by personal concern, those with low health literacy may be more likely to trust this information because of the personal relationship that exists. If members of the social support network do not have adequate health literacy themselves, greater misunderstandings may arise.

Finally, family caregivers and other family members actively seek information about the illness from the patient’s healthcare providers [9,27]. Notably, healthcare providers give more cancer information to the family than to the patient [28]. Further, family members consistently report that many of their most important and supportive interactions with healthcare providers involve information exchange (e.g., [8,9]). Examples of family caregiver information needs from healthcare providers include offering information on the patient’s prognosis, side effects, test results, and how to manage the patient’s pain while at home. Therefore, healthcare professionals need to answer questions in a straightforward manner and schedule meetings with family members to discuss the illness [9].

Even though some family members may be given considerable information, not all have easy access. Due to privacy laws, medical information cannot be shared with just anyone who demonstrates concern. A niece will not likely receive information about her aunt’s condition directly from the aunt’s oncologist unless the aunt has provided written consent. If a family member does not have direct access to the treating physician, but has a strong desire to gather information, he or she is likely to pursue other sources. Individuals who are not primary caregivers frequently use the Internet to find information on a loved one’s cancer [22]. The impact of this information on the decision-making process is unknown, but an individual with low health literacy may not be able to adequately assess the quality of information being provided by a loved one who has gathered information through the Internet.

In essence, family caregivers play a significant role in aiding the cancer patient in learning about and managing cancer information. Accordingly, understanding the impact of this vitally important role in the context of cancer literacy is long overdue. Though no research has specifically examined family caregiver health literacy levels, some studies have examined how well family caregivers comprehend health information. Further, health literacy scholars have begun to recognize that third parties can be influential in understanding patient health literacy. To begin specifically linking the family caregiver role with health literacy in the cancer context, we now turn to this research.

2. Health information-seeking and decision-making

I spent so much time researching treatment options and trying to understand, so, you know, we could talk about what we were going to do, and all. I knew he needed me to do this for him because he felt so bad so much of the time, but, frankly, I needed to do it for myself, too—Agnes

Information, defined as “stimuli from a person’s environment that contribute to his or her knowledge or beliefs” (29: p. 259), is a vital aspect of health communication. Specifically, informed patients feel a sense of control, can cope with uncertainty about their health, follow their plans of care more closely, and recover faster and more thoroughly compared with less informed patients [25]. Further, “informed patients not only have better outcomes, but they also truly communicate with those who provide health services” (30: p. 117). Though patients and healthcare providers are the main focus of health information management, social networks can also play an integral role. Namely, one’s social network (particularly family...
2.1. Family as information providers and decision-makers

Cancer patients and their families have information needs and have vital information to offer to healthcare providers. As cancer patients typically manage their treatment within the context of their social support network, others will be intimately involved across the continuum of care. Further, family members are important health information sources for both patients and healthcare providers. Specifically, informal caregivers who accompany patients to medical appointments serve as information sources for a physician [17], which tends to be a positive experience for all involved. Namely, physicians, patients, and patients’ companions all believe that the companion’s presence is helpful in increasing understanding of the patient’s medical problem, diagnosis, and appropriate treatment [31].

While family members can provide important information across the continuum of care, most (81%) cancer patients prefer receiving their diagnosis alone with the doctor and a notable minority (37%) does not directly share their diagnosis with any member of their social network [32]. Individuals who do not share their diagnosis or related fears and concerns report lower levels of social support [33]. With the consistent findings that social support enhances well-being and coping, those who are reluctant to share their medical condition with others are at greater risk for poor outcomes and limit effective information exchange by the formal and informal healthcare team. Most cancer patients, however, do share their condition with significant others. When they learn of the condition, social support members are highly motivated to seek relevant information so that they can contribute to managing this health crisis effectively [22].

When cancer information is exchanged between relational partners, it is typically provided by family members and targeted toward patients. For example, patients prefer receiving nutrition information from family members, followed by friends and neighbors, then finally from doctors and nutritionists [34]. Further, cancer patients, among others, rate useful informational social support from spouses, romantic partners, friends, and acquaintances as helpful [35]. Once patients are diagnosed with prostate cancer, wives and adult children ensure that patients have knowledge of the disease and treatment options [36].

This information provision can often translate into family caregiver’s assistance with medical decision-making and actual physical care. In the context of cancer care where treatment options are increasing, family member involvement in decision-making is particularly likely [37]. Family members of those in palliative/hospice stages of cancer take an active health decision-making role and physically care for the patient [27]. Further, nurses delegate as much home healthcare as possible to family members [18]. Family members who assist with care or in making health decisions for cancer patients should thus be a primary focus of health literacy researchers, as their potential inability to comprehend health information will likely influence what choices they make and the actual implementation of the cancer patient’s care.

2.2. Family as active information seekers

A second important information role of family caregivers is seeking information about the patient’s illness from healthcare providers. Indeed, both patients and their spouses believe that spousal information needs are important [38] and cancer patients’ spouses are accordingly viewed as “primary information gatherers” (36: p. 148). Despite the central information-seeking role of family members, healthcare providers and family members each tend to downplay the family member information-seeking role [27] and may find barriers to accessing healthcare professionals regarding their loved one’s condition.

Family members tend to be frustrated about how healthcare providers share information with them. In fact, difficulty learning information is the fourth-most mentioned problem for next-of-kin of adult cancer patients [39] and unsatisfactory communication by healthcare providers (including too little information, too much information, and/or abrupt or blunt sharing of information) is named the second highest reason for suffering by cancer patients and their families [40]. Family members complain that they are provided with too many details upon receiving the diagnosis by healthcare providers and thus are unable to process most of the information [17, 28] or that they have difficulty acquiring diagnosis, prognosis, treatment, and recovery information from healthcare providers [17, 27, 38].

2.3. Linking family caregiver information roles with cancer literacy

In terms of information sharing, low health literacy can impact patients’ sharing of medical history with physicians [41]. Failing to share vital information is especially troubling when considering that approximately 70% of a patient’s prior medical history is provided via direct communication [41]. Patient information sharing can be affected by low health literacy in specific ways, including incorrectly understanding what information physicians seek, not grasping health vocabulary in a way that allows for accurate reporting of symptoms, and sharing information out of sequence or illogically [41]. The above statistics paint a grim portrait of information management between patient and healthcare provider and further emphasize the significance of family caregiver health literacy assessment. However, one problem that can arise is that different individuals may remember the “facts” differently, thus providing the healthcare professional with conflicting information.

Although an individual with low health literacy may be hiding this fact from significant others and may attend
appointments without a companion, healthcare providers should consider the possible reasons when a companion is present. Indeed, many patients with low literacy skills report having a family member attend medical appointments in order to serve as a “surrogate reader” [42]. Though not a primary focus of health literacy researchers, a family member’s presence at a medical appointment could be a practical clue for healthcare providers that the patient may not be health literate (e.g., [26,34]), although it may also signal other issues, such as cognitive impairment. When a family member or companion assists in the reading of medical forms and documents [34] or acts as a linguistic translator who clarifies information for the patient [17], this can indicate that the patient does not have adequate levels of health literacy. The fact that minimal education, a typical correlate of low health literacy, positively predicts bringing a companion to the doctor’s office also fits this pattern [43]. The importance of health literacy is also highlighted when considering how much patients rely on their social networks for health information, decision-making, and physical care. Namely, those with low literacy skills tend to consult their families for nutrition information [34]. Further, caregivers may be lacking in health literacy themselves. For example, more than half of Bahrainian caregivers (53%) know that the patient suffers from a mental disorder but cannot correctly specify which disorder [44]. In an interaction analysis of a father giving bad news to his son about his mother’s cancer prognosis, the father has difficulty articulating all of the diagnosis and treatment options to his son [19]. Finally, some family caregivers feel scared, upset, and overwhelmed that medical duties delegated to them by home healthcare nurses are too technical or difficult [18]. Therefore, healthcare providers should be vigilant not only in assessing their patients’ literacy levels but that of the patients’ caregivers as well.

When patients’ social network members offer inadequate information or advice, patients see such communication as unhelpful [35]. Cancer misinformation, in particular, is perpetuated by fear and a reliance on informal information networks [25]. This misinformation can be a result of inadequate family caregiver health literacy levels. Failing to consider family caregiver health literacy, especially in the context of cancer care, can result in a number of potentially negative outcomes, such as frustration and increased stress, concern and confusion regarding the quality of information being provided, and the higher possibility that vital information will not be shared with the healthcare professionals.

Family caregivers may become frustrated at not being useful sources of health information and subsequently may feel as if they are not adequately fulfilling the caregiver role. Though a highly valued role in most families, providing care to a family member can be stressful and demanding, leading to a lack of sleep, financial concerns, and worry over the patient’s well-being [45–47]. Certainly, concerns about whether or not caregivers feel that they have adequate information to guide and support the cancer patient can only add to caregivers’ stress.

The patient may grow concerned about the quality of information provision by the family caregiver and be uncertain how to employ that knowledge when making health decisions. This confusion over the quality of information is highly likely to occur when multiple sources of information are being accessed. Family members may feel particularly compelled to suggest any and all measures to help “save” a loved one [7]. In addition, it may be difficult for cancer patients to label information provided by a loved one as inaccurate because of the emotional entanglements and consequences of “accusing” a loved one of providing “bad” information. For cancer patients and their family members with low health literacy, accessing and assessing the quality of information from conflicting sources may be especially problematic.

Finally, healthcare providers may be unable to gather sufficient information from the family caregiver when diagnosing and treating the patient. Just as a patient with low health literacy may not understand what the doctor is asking or how to share relevant information, a family member with low health literacy will have problems providing relevant and accurate information to the doctor. Any or all of these circumstances can potentially lead to less effective cancer treatments and outcomes.

Individuals with low health literacy feel overwhelmed by their medical diagnosis and make fewer inquiries compared with those with high health literacy [41]. Thus, the presence of family members at medical appointments is vital. Approximately one-third of appointments with physicians include a companion [43,48]. These companions are most likely patients’ family members and they fill various roles, including communicating patient concerns to the doctor, aiding patients in recalling physician recommendations, helping patients make decisions [31], and learning information [49].

3. Conclusions

Health communication scholars underscore the importance of acknowledging and including multiple perspectives, including the relationship between the physician, the patient, and the family caregiver (e.g., [2]) but this has not been extended to the relatively new subject of health literacy. As this position paper shows, family caregivers play a significant role in the diagnosis, treatment, and recovery of individuals with cancer. Thus, the extent to which family caregivers can comprehend the health information they receive along with the patient is crucial for the patient to achieve the most successful health outcome.

4. Practice implications

This position paper has thus far linked research on family caregiving and health information with the importance of cancer literacy. In doing so, it has depicted a disturbing pattern where family members are important sources of health information, informal caregivers who learn and enact medical procedures, and influential aspects of patients’ healthcare and treatment decision-making, yet are not seriously considered by practitioners and researchers in terms of the assessment and improvement of health literacy. To acknowledge the impact that family caregiver health literacy could have on patient health
outcomes, health literacy scholars should assess family caregiver health literacy. Specifically, targeted practical recommendations for understanding family caregiver health literacy in the cancer context are described below.

4.1. Assess family member health literacy

Because low levels of health literacy have a negative impact on medical outcomes, healthcare professionals should assess the literacy levels of their patients as well as that of their family members. While such assessments should start with the patient, family caregivers will likely be highly involved in care provision. Because one sign that patients are not health literate is when they bring family members to medical appointment to both provide and seek information from healthcare providers (e.g., [41,42]), assessing family members’ health literacy is the most crucial recommendation regarding family caregivers. Williams et al. [41] recommend that relatives of low health literacy patients be included in patient medical interviews and information sessions; this inclusion should also involve health literacy assessment. Measuring family member health literacy can be done by healthcare providers in much the same way that patients are assessed, including informally posing open-ended questions or requests to read written health information, and/or the formal administration of short surveys, tests, or interviews [42,50]. If healthcare providers determine that patients and their family members possess similar health literacy levels, they can adapt their communication to both parties accordingly, and/or seek additional help for the family through formal social services or informally through the larger social support network. If the family member has higher levels of health literacy than the patient, the healthcare provider can focus on patient comprehension, while occasionally ensuring that the family member also understands the information.

While assessing levels of health literacy remains challenging and time consuming, quality care cannot be achieved without such assessments. Considering the unique challenges of assessing multiple parties, healthcare providers need more tools and strategies to improve this process. One specific strategy is for healthcare providers to preface health literacy assessment requests by stating that because the family member is important in the healthcare process, they are going to ask both parties to answer questions and provide information. Caregivers seek healthcare provider respect and want to provide information to assist the patient but often are treated dismissively [17]. Thus, if the healthcare provider includes family members in the assessment of health literacy in this manner, it will hopefully aid in the family member feeling as if he or she is usefully assisting both the patient and the healthcare provider.

4.2. Train close relational partners to be peer health educators

Davis et al. [26] recommend recruiting community members to serve as peer educators and information sources to improve health literacy. Macario et al. [34] also suggest creating nutrition interventions that incorporate low literacy patients’ social networks. This suggestion could extend to eliciting the aid of patients’ close relational partners in a similar manner. Not only would this second suggestion require relational partners’ health literacy assessment, patients who receive health information from a personalized source may feel increased comfort. This evaluation process in turn may make patients more likely to seek health information or advice and be willing to indicate what they do and do not understand. Due to the numerous duties that a family caregiver typically takes on in caring for the patient, another individual who is close to the patient should instead be chosen for this training to not overwhelm the family caregiver.

4.3. Provide cancer information directly to family caregivers

Upon receiving the patient’s acute leukemia diagnosis, many relatives feel that receiving written information about leukemia would be helpful [28]. Thus, as our third suggestion, healthcare providers may want to provide family members with their own set of written cancer materials that replicates what is provided to the patient and direct them to additional resources, such as trusted websites or support groups or providing relevant medical information through audiovisual means [42]. Ensuring that family members have needed information shows that healthcare providers recognize the importance of family members in the healthcare process and provides an additional informational resource to the patient. In other words, if written or audiovisual materials are distributed to the patient and family members, the likelihood that at least one of them will read or view and attempt to understand this vital health information increases. Further, such materials may be an innocuous route to initiating a dialogue about cancer between the patient and the family member that could ultimately improve later discussions of treatment options and other medical decisions.

4.4. Improve health interactions between family caregivers and patients

The fourth recommendation seeks to improve interpersonal communication between the cancer patient and family member. Though patients’ social support is consistently linked with improved mental and physical health outcomes [12], cancer-related communication between patients and family members is often characterized by avoidance and difficult interactions [51] that can create additional marital stress [37]. Couples who openly and directly communicate may have difficulty sharing their feelings about cancer [33,52]. Further, when partners’ willingness to discuss cancer mismatch, difficulty in each individual’s adjustment to the illness can result [51]. If healthcare providers design and implement techniques for facilitating cancer-related communication between patients and family members, not only will the patient’s health outlook improve, but patients may be
encouraged to employ family members as additional informed cancer resources. This should increase the likelihood that the information shared is accurate.

In particular, the topic of health literacy should be encouraged in an interpersonal context. Individuals with low health literacy levels are typically ashamed [42] and 67% do not admit it to their spouses [53]. Further, more than half of low health literate individuals do not inform their children and almost 20% have never told anyone. Obviously, failing to disclose low health literacy to close relational partners means that they cannot assist in the healthcare process. Thus, one fundamental communicative aspect of health literacy research should be to create practical methods for close relational partners to initiate and manage conversations about health communication in general and health literacy in particular that are simultaneously effective and that maintain the dignity of the individual with low health literacy.

4.5. Integrate theoretical perspectives into the understanding of family caregiver health literacy

The fifth recommendation is to understand family caregiver health literacy from a theoretical viewpoint. Obviously, the theory that is most applicable to both the family and the health contexts is systems theory. Although systems theorists struggle to effectively integrate the study of family into the context of health [54] there is hope for what the future holds [55] as these spheres become better integrated.

Communication Privacy Management (CPM) theory [56] can also shed light on how family caregivers’ health literacy can impact cancer outcomes. In particular, topic avoidance processes are of interest to CPM theory scholars. Because cancer patients and family members tend to avoid health-related interactions [51], how they do so would be a worthwhile topic to pursue through a CPM theoretical lens. One of this approach’s great strengths is its acknowledgment that relational interactions involve multiple goals beyond information exchange. Thus, CPM is a theoretical lens that helps researchers examine how to achieve multiple, potentially conflicting, goals so that, for example, being open about low health literacy does not become face-threatening.

Finally, communication-centered uncertainty theories may be fruitful for a greater theoretical understanding of family caregiver health literacy. Uncertainty and communication in the context of health is theoretically approached via uncertainty management (e.g., [29]), problematic integration (e.g., [57]), and the Theory of Motivated Information Management (e.g., [58]). Each approach highlights the importance of effectively managing uncertainty about an illness or diagnosis, which is certainly inherent in the concept of health literacy. Further, recent research on uncertainty within families (e.g., [59]) suggests a natural extension of these uncertainty theoretical approaches in the context of family caregiver health literacy and to understanding why families may want to remain uncertain about potential outcomes.

4.6. Improve patient and family caregiver health literacy

The final recommendation is for healthcare providers to improve multiple aspects of patient and family caregiver health literacy. Further, they should expand the conceptualization of health literacy assessment to include cultural and conceptual knowledge and listening and speaking skills in addition to written/reading skills and numeracy. Namely, understanding the ways in which cultural beliefs impact how individuals and their family members manage health information provides another facet to increasing cancer knowledge and comprehension (e.g., [60]). Including family members in understanding cultural/conceptual knowledge of health literacy is also relevant because family interactions provide cultural assimilation.

Essentially, communication is paramount throughout—communication between healthcare providers and patients, healthcare providers and family caregivers, patients and the family caregivers, and health communication researchers and healthcare providers—to establish valid, reliable assessments of multiple facets of health literacy that can be administered with little time commitment and face threat. In initiating these multiple dialogues, this position paper hopes to not only focus research attention on the role of the family caregiver but also to improve both patients’ and their health literacy levels. Because “adequate health literacy is a critical ingredient of quality health in America” (30: p. 117), doing so can only improve the experiences of those who are diagnosed with cancer and their families.

The 5-year mark is this summer; God-willing, we’ll be cancer survivors. . . .—Agnes

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References


