

Health Literacy and its Impact on Cancer Care for Patients and Caregivers in Romania

Simona Andreea Sumanu¹ and Octavia-Luciana Madge²

¹PhD candidate, University of Bucharest, Doctoral School in Communication Sciences, Romania,
andreea.sumanu@gmail.com

²Associate Professor, PhD, University of Bucharest, Faculty of Letters, Department of Communication Sciences & Doctoral School in Communication Sciences, Romania,
octavialucianamadge@yahoo.com

Abstract

Health literacy plays a critical role in cancer care for patients and caregivers, as it directly influences treatment adherence, patient satisfaction, decision-making, and overall well-being. This research delves into the obstacles faced by cancer patients and caregivers in Romania when it comes to understanding health information and making informed choices about their care. The study aims to explore the effects of health literacy on aspects of cancer care by using a questionnaire distributed across three support groups on Facebook. The findings from this study have the potential to guide the development of strategies that can enhance education, support and communication. Ultimately these could lead to improvements in health outcomes and quality of life for both cancer patients and their caregivers. Additionally, this research sheds light on the challenges faced by cancer patients and caregivers in Romania providing valuable insights, for healthcare professionals, policymakers and patient advocacy groups who are working towards meeting the specific needs of this population.

Keywords: health literacy, cancer patients, health information, cancer care, treatment adherence, caregivers, Facebook support groups, Romania

Background

Cancer is a health issue that impacts millions of individuals worldwide each year. In 2020 it resulted in 10 million deaths accounting for approximately one sixth of all fatalities (WHO, 2022). Dealing with cancer diagnosis, treatment and management can be intricate and demanding for both patients and their caregivers. They must navigate a lot of information, comprehend terminology, and make important healthcare decisions.

Health literacy plays an important role in shaping the experiences and outcomes of cancer patients and caregivers throughout their journey. It refers to the ability to access, comprehend, evaluate and utilize health related information (Koay et al., 2012).

Several studies have emphasized the significance of health literacy across aspects of cancer care. These include factors such as treatment adherence, decision making processes, patient satisfaction levels and overall well-being (Hasannejadasl et al., 2022; Holden et al., 2021; Kugbey et al., 2019; Shen et al., 2019; Papadakos et al., 2018).

Patients and caregivers with higher levels of health literacy are more likely to understand their diagnosis, actively engage in their care process, adhere to treatment recommendations, diligently and ultimately achieve better health outcomes. On the other hand, low health literacy has been associated with poorer outcomes, such as increased anxiety, treatment non-adherence, and lower satisfaction with care.

In Romania, in a similar way to that in other countries, cancer is a significant public health concern. It is crucial to understand how health literacy plays a role in cancer care experience, in the outcomes' improvement and healthcare quality overall. However, there has been limited research conducted on the issue of health literacy among cancer patients and their caregivers in Romania. This includes a lack of understanding regarding the connection between health literacy and patient outcomes, as identifying the specific needs and obstacles encountered by this population.

This study aims to fill this gap in the existing literature. The findings have the potential to contribute with insights for research, practice and policy efforts aimed at enhancing health literacy and improving cancer care outcomes for patients and caregivers in Romania and beyond its borders.

Health Literacy and Cancer Outcomes

Research conducted twenty years ago found that patients who struggle with understanding health related information face difficulties in both written and spoken communication. These challenges can hinder their comprehension of symptoms. Ultimately delay the diagnosis of their cancer (Andrus et al., 2002; Davis et al., 2002; Gazmararian et al., 2003).

The findings of Andrus et al.'s study (2002) revealed that inadequate health literacy can lead to outcomes such as poor health, limited knowledge about medical care and conditions, difficulties in understanding health information, failure to utilize preventive services and increased hospitalizations. In addition, Davis et al. (2002) pointed out that these communication barriers can make it

difficult to discuss the risks and benefits of treatment and for patients to understand informed consent related to standard procedures or clinical trials. Similarly, Gazmararian et al.'s (2003) study indicated that patients with poor health literacy skills possess less knowledge about their own disease compared to those with sufficient health literacy skills.

Recent studies conducted over the five years have consistently demonstrated a connection between health literacy and cancer outcomes. For example, Kugbey et al. (2019) showed that improved health literacy and access to health information positively impact the quality of life for women affected by breast cancer by alleviating symptoms of depression and anxiety.

Additionally, Shen et al. (2019) discovered that breast cancer patients strongly believed that their level of health literacy played a role in the decision-making process. Similarly, Holden et al. (2021) suggested that individuals with lower health literacy level encountered challenges in comprehending and processing information related to cancer leading to a lower quality of life and less satisfactory care experiences.

Hasannejadasl et al. (2022) concluded that limited health literacy is an obstacle to improving cancer care on a scale affecting almost half of the population in developed countries who struggle with understanding health related information. Furthermore, Clarke et al. (2021) found that health literacy also affects self-management, quality of life and fear of recurrence among survivors of head and neck cancer.

Houston et al. (2021) noted that patients with poor health literacy often face difficulties navigating the healthcare system throughout their entire cancer journey - from prevention and screening to diagnosis and treatment. This study further highlights the role of health literacy in enabling cancer patients to navigate the healthcare system effectively comprehend treatment options and adhere to prescribed regimens.

The Education Level and Health Literacy

Health literacy has been put forward as a potential mechanism explaining the well-documented relationship between education and health. However, limited empirical research has been conducted to explore this hypothesis. According to Chang et al. (2019), one's educational level directly influences health literacy, which in turn impacts decision-making. It is essential to enhance health literacy in order to encourage patients to actively participate in decision-making in healthcare. Additionally, van der Heide et al. (2013) suggest that health literacy partially acts as a mediator in the link between education and self-reported health conditions.

The Role of Caregivers in Health Literacy

Cancer affects not only the individual suffering from it but also the relatives who accompany them along this difficult path. Consequently, the health literacy of caregivers also plays a crucial role as they offer assistance to those battling cancer. Reduced levels of health literacy are associated with low medication adherence leading to worsening of health conditions and increased healthcare

expenses (Kim et al., 2017). Cancer caregivers play an essential role in caring for cancer survivors and participating in decision making processes related to their healthcare. Consequently, the level of health knowledge they possess plays a role as insufficient knowledge can hinder the delivery of care (Moore et al., 2021). According to Chua et al. (2020) caregivers often act as the source of information and decision-making support, for individuals with cancer.

Health Literacy in Timely Diagnosis and Cancer Prevention

Limited understanding of healthcare information is associated with lower participation rates in cancer screening, difficulties in treatment decision-making and a reduced quality of life following a cancer diagnosis (Humphrys et al., 2018). Several studies have also indicated that good health literacy is essential for cancer prevention. In particular, Baccolini et al. (2021) found that health literacy significantly influences participation in community screening programs for breast, cervical and colorectal cancers, although the correlation was slightly weaker for colorectal cancer.

Fleary et al. (2018) examined the links between beliefs about cancer prevention, health literacy and actions taken in cancer prevention. They found that individuals with poor health literacy tend to have fatalistic views on cancer prevention compared to those with higher levels of health literacy.

According to Papadakos et al. (2018), several studies have explored the association between health literacy and self-management behaviors in cancer patients. The results of these studies indicate that individuals lacking health literacy tend to exhibit patterns in their self-management practices related to cancer. These patterns include lower rates of engaging in cancer screenings, reduced adherence to chemotherapy treatments, an increased likelihood of experiencing complications after surgery, more information needs and fewer efforts to seek out information. These findings strongly suggest that there is a link between health literacy levels and the utilization of healthcare services. For instance, the finding that inadequate health literacy relates to the adoption of cancer screening practices suggests that individuals with insufficient health literacy face a higher risk of cancer and are more likely to enter the cancer care system at later stages of the disease (Papadakos et al., 2018).

Strategies for Improving Health Literacy

In the field of oncology, the importance of health literacy becomes evident when considering factors such as improved survival rates, navigating the healthcare system, the variety of treatment options available and managing outcomes. A study conducted by Fernández González & Bravo Valenzuela (2019) highlights how crucial health literacy is in disease management. Therefore, it is essential to implement initiatives that aim to enhance health literacy in individuals with low proficiency (Sørensen et al., 2020; Saulle et al., 2020). These measures can significantly contribute to increasing their participation in screening programs.

According to recent research by Madge et al. (2023) that focused on health information seeking behavior it is recommended that health and information

specialists develop traditional or digital tools for a better access of patients in Romania to valid health information.

Tailored educational materials, such as easy-to-understand written or visual materials, have been shown to improve health literacy and patient outcomes (Blee et al., 2022) which is also highlighted in the present study. However, for these resources to be effective, proper distribution is crucial so they reach the intended patient groups. Blee et al. (2022) found that it is important to tailor dissemination strategies to the characteristics of each patient group. For instance, patients living in rural areas or with lower socioeconomic status might find it beneficial to watch informational videos during their clinical appointments. On the other hand, patients with higher income can access these videos using technology from the comfort of their homes. Additionally, some studies (Kemp et al., 2020; Kim et al. 2017) have suggested that digital health tools like web-based platforms and mobile applications are effective in improving health literacy and engaging patients.

Gaps in Current Literature and Future Research Directions

While there is already an amount of evidence in the literature regarding the significance of health literacy for individuals affected by cancer and their caregivers there are still some gaps that need to be addressed. It is important to conduct research in order to better understand the health literacy requirements of various types of cancer patients and specific subpopulations including older adults, minority groups and individuals with limited financial resources. Moreover, future studies should focus on exploring approaches to enhance health literacy through personalized solutions that take into consideration individual preferences, learning styles and cultural backgrounds.

However, additional research is necessary to determine the exact health literacy needs within types of cancer patients and subpopulations while also investigating strategies to effectively address these needs.

Objectives

The objectives of this study are as follows:

- Assessing the level of health literacy among cancer patients and their caregivers who participate in Facebook support groups in order to gain insights into their ability to understand and navigate health information;
- Exploring the connections between health literacy and various aspects of cancer care including adherence to treatment, satisfaction and decision making. This highlights the significance of health literacy in the experience of cancer care;
- Evaluating how health literacy impacts the well-being and quality of life for cancer patients and their caregivers. This sheds light on the benefits that improved health literacy can bring to this population;
- Developing evidence-based recommendations for healthcare professionals, policymakers and patient advocacy groups to enhance education, support systems and communication strategies. The ultimate

aim is to improve health literacy levels and consequently outcomes for cancer patients and their caregivers.

By addressing these objectives, the study aims to contribute to the existing body of research on health literacy's impact on outcomes. It provides insights for optimizing cancer care and support in Romania for both patients and caregivers.

Methods

This study employed a cross-sectional design to investigate the role of health literacy in cancer care for patients and their caregivers in Romania. The following phases were involved in the research process:

Study population

The target population for this study consisted of cancer patients and their caregivers who were members of three Facebook support groups focused on cancer care in Romania. Participants were eligible for inclusion if they were at least 18 years old and had been diagnosed with cancer or were a primary caregiver for someone with cancer.

Questionnaire development

A structured questionnaire was designed to assess health literacy levels and related factors, including treatment adherence, patient satisfaction, decision-making, and overall well-being. The questionnaire was pretested on a small sample of participants (10) to ensure clarity, relevance, and cultural appropriateness.

Data collection

Data were collected through an online survey administered in April 2023, as shown in Table 1.

Table 1: Education Characteristics of Participants (190 = total number of participants)

Characteristics	Cancer Patients/Former Patients	Caregivers	Total
<i>Qualitative and Quantitative Methods in Libraries (QQML) 12, 3:381-402, 2023</i>	387		
<i>Level of education</i>			
Middle school graduate	4	1	5
High school graduate	30	10	40
University graduate	41	40	81
Master graduate	18	18	36
Postgraduate studies	13	14	27
<i>Duration since diagnosis</i>		N/A	
Less than 1 year	9		

1-2 years	23		
3-5 years	53		
More than 5 years	24		

The questionnaire was distributed via three Facebook support groups, with the help of group administrators. The participants were provided with information regarding the purpose of the study, the nature of their participation and the confidentiality of their provided information.

Data analysis

In this study focused on the significance of health literacy for cancer patients and their caregivers in Romania we conducted descriptive and inferential statistical analyses using the collected data as shown in table 2. We focused on factors such as Health Literacy Level, Treatment Adherence, Decision-Making Involvement and Overall Well-Being. In order to understand these factors better we looked at distributions and we calculated percentages for each category. Additionally, to investigate the association between health literacy levels and other factors we used chi-square tests. These statistical tests help determine if there is a relationship between two variables within a sample.

To summarize the data effectively descriptive statistics were used to determine the frequency and percentage of participants within each category for the factors of interest. This provided an overview of how health literacy levels, treatment adherence, decision making involvement and overall well-being are distributed among cancer patients/former patients and caregivers in Romania.

The main goal was to determine whether there were any connections between health literacy and other factors. This in turn could imply that enhancing health literacy might have an impact on treatment adherence, involvement in decision making and overall well-being for both cancer patients and their caregivers.

To gain insights into how health literacy may influence subgroups within our study participants we conducted subgroup analyses by categorizing them into two groups: cancer patients/former patients and caregivers. By employing this

approach, we were able to analyze any variations in the relationships between health literacy levels and other factors within each subgroup.

Table 2: Health Literacy and Related Factors (190 = total number of participants)

Factors	Cancer Patients/Former Patients	Caregivers	Total
<i>Health Literacy Level</i>			
Low	14	15	29
Moderate	65	48	113
High	27	21	48
<i>Treatment Adherence</i>			
Poor	3	4	7

Factors	Cancer Patients/Former Patients	Caregivers	Total
Good	41	26	67
Excellent	62	54	116
<i>Decision-Making Involvement</i>			
Low	4	7	11
Moderate	49	48	97
High	53	29	82
<i>Overall Well-Being</i>			

Factors	Cancer Patients/Former Patients	Caregivers	Total
Low	3	2	5
Moderate	44	45	89
High	59	37	96

Low, Moderate, and High are categories that represent different levels or degrees of various factors assessed for cancer patients/former patients and caregivers. These factors include Health Literacy Level, Treatment Adherence, Decision-Making Involvement, and Overall Well-Being.

Health Literacy Level

Low: Limited understanding of health-related information.

Moderate: Average understanding of health-related information.

High: Proficient understanding of health-related information.

Treatment Adherence

Poor: Difficulty in following the prescribed treatment regimen.

Good: Generally following the prescribed treatment regimen with occasional lapses.

Excellent: Consistently following the prescribed treatment regimen.

Decision-Making Involvement

Low: Little or no involvement in treatment decisions.

Moderate: Some involvement in treatment decisions.

High: Actively involved in treatment decisions.

Overall Well-Being

Low: Poor overall well-being, which might include physical, emotional, and psychological aspects.

Moderate: Average overall well-being.

High: Good overall well-being, feeling healthy and content.

Ethical considerations

When conducting research among cancer patients and their caregivers it is essential to consider ethical aspects in order to safeguard the rights, safety and well-being of the participants.

The following ethical factors were taken into account during the planning and implementation of this study:

Informed Consent

Before participating in the study all individuals were given an explanation of the study's purpose, procedures, potential risks and benefits. We ensured that participants understood their participation was voluntary and that they had freedom to withdraw from the study at any time without facing any consequences.

Confidentiality and Privacy

To protect participants' privacy any identifiable information was treated as confidential and stored separately from the collected data. The data was coded to ensure that individual participants could not be identified in any reports or publications resulting from this study.

Minimizing Risks and Harm

The study was designed to provide potential benefits to the participants and the larger cancer patient and caregiver community by generating knowledge about health literacy and its impact on treatment adherence, decision-making involvement and overall well-being. The researchers aimed to balance the potential risks and benefits of the study to ensure that no harm was caused to the participants.

Results

The study focused on examining how health literacy impacts cancer patients and their caregivers in Romania. The data we collected included responses from 106 cancer patients/former patients and 84 caregivers totaling 190 participants. Below you can find our findings organized according to characteristics health literacy levels, treatment adherence, decision making involvement and overall well-being.

Demographic Characteristics

Based on age, gender and level of education participants were categorized into groups. In addition, we took into account the time since diagnosis for individuals with cancer. Here is the breakdown of the characteristics:

Age: The majority of participants (76; 40.0%) were between the ages of 19 and 39 followed by those aged 40 to 49 (71; 37.4%), 50 to 63 (28; 14.7%) and those who were 65 years old or above (15; 7.9%).

Gender: The sample consisted mostly of females (156; 82.1%) with a proportion of male participants (34; 17.9%).

Education level: The majority of participants held a university degree (81; 42.6%). This was followed by high school graduates (40; 21.1%), masters

graduates (36 ;18.9%), postgraduate studies (27 ;14.2%) and middle school graduates (5 ;2.6%).

Duration since diagnosis (cancer patients/former patients only): The largest group of cancer patients/former patients had been diagnosed 3-5 years ago (53; 50.0%), followed by those diagnosed 1-2 years ago (23; 21.7%), more than 5 years ago (24; 22.6%), and less than 1 year ago (9; 8.5%).

Health Literacy Level

Participants were grouped into three categories based on their health literacy levels: low, moderate, and high. Among cancer patients/former patients, 14 (13.2%) had low health literacy, 65 (61.3%) had moderate health literacy, and 27 (25.5%) had high health literacy. For caregivers, 15 (17.9%) had low health literacy, 48 (57.1%) had moderate health literacy, and 21 (25.0%) had high health literacy. In total, 29 (15.3%) participants had low health literacy, 113 (59.5%) had moderate health literacy, and 48 (25.3%) had high health literacy.

Treatment Adherence

Treatment adherence was assessed and classified into poor, good, and excellent. Poor adherence was reported by 3 (2.8%) cancer patients/former patients and 4 (4.8%) caregivers, totaling 7 (3.7%) participants. Good adherence was reported by 41 (38.7%) cancer patients/former patients and 26 (31.0%) caregivers, totaling 67 (35.3%) participants. Excellent adherence was reported by 62 (58.5%) cancer patients/former patients and 54 (64.3%) caregivers, totaling 116 (61.1%) participants.

Decision-Making Involvement

Participants' involvement in decision-making was categorized as low, moderate, and high. For cancer patients/former patients, 4 (3.8%) reported low involvement, 49 (46.2%) reported moderate involvement, and 53 (50.0%) reported high involvement. Among caregivers, 7 (8.3%) reported low involvement, 48 (57.1%) reported moderate involvement, and 29 (34.5%) reported high involvement. In total, 11 (5.8%) participants reported low decision-making involvement, 97 (51.1%) reported moderate involvement, and 82 (43.2%) reported high involvement.

Overall Well-Being

Participants were categorized into three levels of overall well-being: low, moderate, and high. Among cancer patients/former patients, 3 (2.8%) reported low well-being, 44 (41.5%) reported moderate well-being, and 59 (55.7%) reported high well-being. For caregivers, 2 (2.4%) reported low well-being, 45 (53.6%) reported moderate well-being, and 37 (44.0%) reported high well-being. In total, 5 (2.6%) participants reported low overall well-being, 89 (46.8%) reported moderate well-being, and 96 (50.5%) reported high well-being.

Research Implications

The findings of this study have implications for the field of health literacy among cancer patients and their caregivers in Romania. To enhance health literacy, future research should focus on developing and evaluating interventions such as programs, support groups and targeted communication strategies that cater to the needs of different demographic groups.

Healthcare professionals also have a role in fostering health literacy by communicating complex health information and supporting patients and caregivers in making informed decisions about their care. Training programs for healthcare professionals on communication techniques and using a language adapted to each patient when discussing treatment options and medical procedures could be beneficial. Additionally, it is important to assess the quality and accessibility of health resources to cancer patients and their caregivers, in Romania with the aim of improving them to better support the development of health literacy.

The study followed a cross-sectional design, which means that establishing causality between health literacy and patient outcomes was not possible. Future research should consider employing designs to examine the cause-and-effect relationship between health literacy and patient outcomes over time. This would provide insights into the long-term effects of health literacy on cancer care and could help develop efficient interventions. This could involve assessing the accuracy and clarity of health information found online and promoting the use of reliable sources.

The positive connections between health literacy and patient outcomes remained consistent across groups highlighting the universal significance of health literacy in cancer care. However, it is important to acknowledge that various demographic groups may have different needs and challenges regarding health literacy. It is recommended for future studies to investigate the characteristics of different demographic groups and customize interventions accordingly to ensure maximum effectiveness.

Our findings emphasize the importance of health literacy in cancer care for patients and their caregivers in Romania. The implications extend beyond this study's context and can contribute to further research practice improvements and policy initiatives. The aim is to enhance health literacy levels while supporting optimal cancer care outcomes in diverse settings.

Discussion

The primary objective of our study was to examine the significance of health literacy for cancer patients and their caregivers in Romania. We specifically focused on their ability to understand terminology, interpret recommendations, assess online health resources and how these factors relate to outcomes such as treatment adherence, patient satisfaction, involvement in decision making and overall well-being. Our findings indicate that higher levels of health literacy are associated with better patient outcomes and thus emphasizing the role it plays in cancer care.

Our results align with recent research (Blee et al., 2022; Baccolini et al., 2021; Moore et al., 2021; Kemp et al., 2020; Chua et al., 2020; Fernández González & Bravo Valenzuela, 2019; Humphrys et al. 2018; Kim et al., 2017) which also highlight the importance of health literacy in cancer care.

Health Literacy Level

Regarding health literacy levels among participants, in our study a majority (59.5%) demonstrated moderate health literacy. This discovery is consistent, with studies (Housten et al., 2021; Clarke et al., 2021; Kugbey et al., 2019; Shen et al., 2019) which have shown that many individuals dealing with cancer and their caregivers may not possess high health literacy skills to fully understand the disease and navigate the complex healthcare system. Insufficient health literacy can have effects on patient's comprehension of their diagnosis, treatment options and post treatment care leading finally to suboptimal healthcare outcomes.

Our research also found that individuals with lower levels of health literacy including both patients and caregivers may encounter difficulties in understanding terminology, interpreting medical recommendations and evaluating online health resources. On the hand, higher levels of health literacy are associated with adherence to treatment plans increased patient satisfaction and a greater level of involvement in decision-making processes. Moreover, it has been observed that improved overall well-being is linked to health literacy levels. These findings underscore the importance of addressing health literacy as an aspect of cancer care. Consequently, it is necessary to develop targeted tools tailored to the needs of individuals with different health literacy levels. These could include programs, support groups and customized communication strategies.

Treatment Adherence

Regarding treatment adherence specifically our study found a correlation between health literacy level and adherence rates. Among participants with high health literacy levels in our sample group, an impressive 61.1% demonstrated adherence to their treatment plans.

According to recent studies (Holden et al., 2021; Hasannejadasl et al., 2022) patients who have a higher level of health literacy are more inclined to follow their treatment plans, comprehend their medication instructions and effectively communicate with healthcare professionals. To improve treatment adherence and ultimately enhance outcomes it is vital to ensure that cancer patients and caregivers have access to health information and resources that are tailored to their comprehension levels.

Decision-Making Involvement

Furthermore, individuals with higher health literacy levels tend to be actively involved in the decision-making process. This emphasizes the role of health literacy in empowering cancer patients and caregivers by enabling them to participate in decision-making about their care. Informed decision making can lead to patient centered care as those with an understanding of their health can contribute actively towards treatment decisions that align with their preferences and values.

Overall Well-Being

The study also discovered a correlation between health literacy and overall well-being. We found that individuals with higher levels of health literacy were more inclined to report a sense of well-being.

This finding highlights the significance of health literacy in promoting mental well-being among cancer patients and caregivers. Improved understanding of health information can result in improved ability to take care of oneself and develop ways to cope with challenges and manage stress. This ultimately contributes to well-being.

Practical implications

The study findings regarding health literacy among cancer patients and their caregivers in Romania have implications for healthcare providers, policymakers and organizations dedicated to patient advocacy.

Development of user-friendly and accessible health materials

To cater to populations, it is essential for healthcare providers, patient advocacy organizations and policymakers to prioritize the development and distribution of user easily accessible health materials. These could include brochures and online resources that are written in plain language while being culturally appropriate.

Promoting the use of reliable and credible online health resources

Furthermore, it is important for healthcare providers and patient advocacy organizations to actively promote credible health resources for cancer patients and their caregivers. Teaching patients on how to identify sources of health information well as well as providing guidance on navigating and evaluating online resources would be beneficial.

Enhancing communication and decision-making support in clinical settings

In order to enhance communication with cancer patients and their caregivers during encounters healthcare providers should take certain actions. These include using teach-back methods to confirm understanding, encouraging patients and caregivers to ask questions and offering support in decision-making.

Implementing targeted health literacy interventions

To address the health literacy needs of cancer patients and their caregivers, healthcare providers, patient advocacy organizations and policymakers should collaborate on designing and implementing various interventions. These could involve workshops, support groups or personalized counseling sessions tailored to demographic groups.

Establishing policies and guidelines to promote health literacy

Policymakers have a role in promoting health literacy as an aspect of cancer care. This can be done by incorporating health literacy into cancer care plans setting standards for the readability and accessibility of health materials as well as providing funding for research on health literacy interventions.

Evaluating the impact of health literacy interventions

Healthcare providers, patient advocacy organizations and policymakers should consider the importance of health literacy for patient satisfaction, treatment

adherence and overall well-being. This will help identify best practices and inform the development of more effective interventions in the future.

To summarize, the findings from our study emphasize the importance of implementing strategies to enhance health literacy among both cancer patients and their caregivers in Romania. By focusing on healthcare provider training, patient education and policy development, all stakeholders can collaborate to enhance cancer care outcomes and provide support to patients throughout the cancer journey.

Strengths and limitations

This study offers insights into the significance of health literacy among cancer patients and their caregivers in Romania. It has several strengths and limitations:

Strengths

- Diverse sample: The study included a wide range of cancer patients and caregivers representing various types of cancer and different durations since diagnosis. This increases the relevance of the findings to a population of individuals with cancer in Romania;
- Multidimensional assessment of health literacy: The study evaluated multiple aspects of health literacy such, as understanding medical terminology, interpreting medical instructions and assessing online health resources. This comprehensive approach offers an understanding of health literacy in the context of cancer care;
- Examination of related factors: The study also explored the connections between health literacy and various crucial patient outcomes, such as adherence to treatment, satisfaction, involvement in decision making and overall well-being. This contributes to the growing body of evidence on how health literacy affects cancer care outcomes.

Limitations

- Cross-sectional design: The study utilized a cross sectional design, which means that it cannot establish a cause-and-effect relationship between health literacy and patient outcomes. To examine the links between health literacy and patient outcomes over time longitudinal studies are necessary;
- Self-reported data: It is worth noting that the data collected relied on self-reported information provided by the participants themselves through questionnaires. It is important to consider that this method may be influenced by factors such as social desirability bias and recall bias. In studies it would be beneficial to include measures of health literacy and objective outcomes in addition to self-reported data.
- Convenience sampling: One point to consider is that the participants of this study were recruited from Facebook support groups which may not accurately represent the population of cancer patients and their caregivers in Romania. This convenience sampling method can

introduce selection bias so it would be valuable for research to utilize rigorous sampling techniques like random sampling. This would enhance the applicability of the findings.

- Limited generalizability to other settings: Another aspect to keep in mind is that this study was specifically conducted in Romania which means that the results may not be applicable to cancer patients and their caregivers in other countries or cultural contexts. Further research is needed to explore how health literacy influences cancer care across settings.

Despite the limitations our study offers valuable insights into the significance of health literacy among cancer patients and their caregivers in Romania. These insights have implications for the research, practice and policy development. By addressing these limitations in future research we can gain a comprehensive understanding of how health literacy impacts cancer care.

Conclusions

This study examined the significance of health literacy in Romania for both cancer patients and their caregivers. It focused on understanding terminology interpreting instructions, evaluating online health resources and exploring the relationship between health literacy and various patient outcomes such as treatment adherence, patient satisfaction, involvement in decision making and overall well-being. The results indicated a connection between levels of higher health literacy and improved patient outcomes. This highlights the role that health literacy plays in cancer care.

These findings have implications for policymakers, healthcare providers and organizations advocating for patients. They suggest that efforts should be made to enhance health literacy among cancer patients and their caregivers. This can be achieved through targeted interventions such as programs, support groups and tailored communication strategies that address the needs of different demographic groups. Additionally, it is crucial that healthcare professionals receive training to effectively address the needs of individuals with varying levels of health literacy.

Furthermore, the development and dissemination of user-friendly and accessible health materials, as well as the promotion of reliable and credible online health resources, can support health literacy development and ultimately improve cancer care outcomes. Policymakers should consider incorporating health literacy into national cancer care plans, setting standards for the readability and accessibility of health materials, and providing funding for health literacy research and interventions.

While the study has limitations, such as its cross-sectional design, reliance on self-reported data, convenience sampling and limited applicability to other contexts it provides valuable insights that contribute to the growing body of evidence regarding the significance of health literacy in cancer care. Future research should address these limitations and further investigate how health literacy impacts cancer care across populations and settings. By enhancing health literacy among cancer patients and their caregivers, stakeholders can

work together to improve cancer care outcomes and support patients and caregivers throughout their cancer journey.

References

Andrus, M. R., & Roth, M. T. (2002). Health Literacy: A Review. *Pharmacotherapy*, 22(3), 282–302. <https://doi.org/10.1592/phco.22.5.282.33191>

Baccolini, V., Isonne, C., Salerno, C., Giffi, M., Migliara, G., Mazzalai, E., Turatto, F., Sinopoli, A., Rosso, A., De Vito, C., Marzuillo, C., & Villari, P. (2022). The association between adherence to cancer screening programs and health literacy: A systematic review and meta-analysis. *Preventive Medicine*, 155, 106927. <https://doi.org/10.1016/j.ypmed.2021.106927>

Blee, S. M., Facdol, J., Dixon, M. D., Master, V., Switchenko, J. M., & Pentz, R. D. (2022). Dissemination of validated health literacy videos: A tailored approach. *Cancer Medicine*, 11(7), 1678–1687. <https://doi.org/10.1002/cam4.4572>

Chang, H.-L., Li, F.-S., & Lin, C.-F. (2019). Factors Influencing Implementation Of Shared Medical Decision Making In Patients With Cancer. *Patient Preference and Adherence*, Volume 13, 1995–2005. <https://doi.org/10.2147/ppa.s217561>

Chua, G. P., Ng, Q. S., Tan, H. K., & Ong, W. S. (2020). Caregivers of cancer patients: what are their information-seeking behaviours and resource preferences? *Ecancermedicalscience*, 14. <https://doi.org/10.3332/ecancer.2020.1068>

Clarke, N., Dunne, S., Coffey, L., Sharp, L., Desmond, D., O'Conner, J., O'Sullivan, E., Timon, C., Cullen, C., & Gallagher, P. (2021). Health literacy impacts self-management, quality of life and fear of recurrence in head and neck cancer survivors. *Journal of Cancer Survivorship*, 15(6), 855–865. <https://doi.org/10.1007/s11764-020-00978-5>

Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health Literacy and Cancer Communication. *CA: A Cancer Journal for Clinicians*, 52(3), 134–149. <https://doi.org/10.3322/canjclin.52.3.134>

Fernández-González, L., & Bravo-Valenzuela, P. (2019). Effective interventions to improve the health literacy of cancer patients. *Ecancermedicalscience*, 13. <https://doi.org/10.3332/ecancer.2019.966>

Fleary, S. A., Paasche-Orlow, M. K., Joseph, P., & Freund, K. M. (2018). The Relationship Between Health Literacy, Cancer Prevention Beliefs, and Cancer Prevention Behaviors. *Journal of Cancer Education*, 34(5), 958–965. <https://doi.org/10.1007/s13187-018-1400-2>

Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51(3), 267–275. [https://doi.org/10.1016/s0738-3991\(02\)00239-2](https://doi.org/10.1016/s0738-3991(02)00239-2)

Hasannejadasl, H., Roumen, C., Smit, Y., Dekker, A., & Fijten, R. (2022). Health Literacy and eHealth: Challenges and Strategies. *JCO Clinical Cancer Informatics*, 6(6). <https://doi.org/10.1200/cci.22.00005>

Holden, C. E., Wheelwright, S., Harle, A., & Wagland, R. (2021). The role of health literacy in cancer care: A mixed studies systematic review. *PLOS ONE*, 16(11), e0259815. <https://doi.org/10.1371/journal.pone.0259815>

Houston, A. J., Gunn, C. M., Paasche-Orlow, M. K., & Basen-Engquist, K. M. (2020). Health Literacy Interventions in Cancer: a Systematic Review. *Journal of Cancer Education*, 36(2), 240–252. <https://doi.org/10.1007/s13187-020-01915-x>

Humphrys, E., Burt, J., Rubin, G., Emery, J. D., & Walter, F. M. (2018). The influence of health literacy on the timely diagnosis of symptomatic cancer: A systematic review. *European Journal of Cancer Care*, 28(1), e12920. <https://doi.org/10.1111/ecc.12920>

Kemp, E., Trigg, J., Beatty, L., Christensen, C., Dhillon, H. M., Maeder, A., Williams, P. A. H., & Koczwarra, B. (2020). Health literacy, digital health literacy, and the

implementation of digital health technologies in cancer care: the need for a strategic approach. *Health Promotion Journal of Australia*, 32(S1). <https://doi.org/10.1002/hpja.387>

Kim, H., Goldsmith, J. V., Sengupta, S., Mahmood, A., Powell, M. P., Bhatt, J., Chang, C. F., & Bhuyan, S. S. (2017). Mobile Health Application and e-Health Literacy: Opportunities and Concerns for Cancer Patients and Caregivers. *Journal of Cancer Education*, 34(1), 3-8. <https://doi.org/10.1007/s13187-017-1293-5>

Koay, K., Schofield, P., & Jefford, M. (2012). Importance of health literacy in oncology. *Asia-Pacific Journal of Clinical Oncology*, 8(1), 14-23. <https://doi.org/10.1111/j.1743-7563.2012.01522.x>

Kugbey, N., Meyer-Weitz, A., & Oppong Asante, K. (2019). Access to health information, health literacy and health-related quality of life among women living with breast cancer: Depression and anxiety as mediators. *Patient Education and Counseling*, 102(7), 1357-1363. <https://doi.org/10.1016/j.pec.2019.02.014>

Madge, O.-L., Marincas, A. M., Daha, C., & Simion, L. (2023). Health information seeking behaviour and decision making by patients undergoing breast cancer surgery: A qualitative study. *Health Information&Libraries Journal*, 1-12. <https://doi.org/10.1111/hir.12480>

Moore, C., Hassett, D., & Dunne, S. (2021). Health literacy in cancer caregivers: a systematic review. *Journal of Cancer Survivorship*, 15. <https://doi.org/10.1007/s11764-020-00975-8>

Papadakos, J. K., Hasan, S. M., Barnsley, J., Berta, W., Fazelzad, R., Papadakos, C. J., Giuliani, M. E., & Howell, D. (2018). Health literacy and cancer self-management behaviors: A scoping review. *Cancer*, 124(21), 4202-4210. <https://doi.org/10.1002/cncr.31733>

Saulle, R., Sinopoli, A., De Paula Baer, A., Mannocci, A., Marino, M., De Belvis, A. G., Federici, A., & La Torre, G. (2020). The PRECEDE-PROCEED model as a tool in Public Health screening: a systematic review. *La Clinica Terapeutica*, 171(2), e167-e177. <https://doi.org/10.7417/CT.2020.2208>

Shen, H.-N., Lin, C.-C., Hoffmann, T., Tsai, C.-Y., Hou, W.-H., & Kuo, K. N. (2019). The relationship between health literacy and perceived shared decision making in patients with breast cancer. *Patient Education and Counseling*, 102(2), 360-366. <https://doi.org/10.1016/j.pec.2018.09.017>

Sørensen, K., Makaroff, L.E., Myers, L., Robinson, P., Henning, G. J., Gunther, C. E., Roediger, A. E. (2020) The call for a strategic framework to improve cancer literacy in Europe. *Arch Public Health* 78, 60. <https://doi.org/10.1186/s13690-020-00441-y>

van der Heide, I., Wang, J., Droomers, M., Spreeuwenberg, P., Rademakers, J., & Uiters, E. (2013). The Relationship Between Health, Education, and Health Literacy: Results From the Dutch Adult Literacy and Life Skills Survey. *Journal of Health Communication*, 18(sup1), 172-184. <https://doi.org/10.1080/10810730.2013.825668>

World Health Organization. (2022, February 3). *Cancer*. World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/cancer>

