

Tell me why. Tell me more. (Absent) educational messages as memorable messages in the cancer trajectory

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Summary

Background. Certain educational messages received in the cancer trajectory can be remembered for a long time and significantly impact patient's behavior, thus becoming memorable messages.

Aims. To identify, reconstruct, and analyze the absent or present educational messages considered memorable by breast cancer patients.

Methods and procedures. Qualitative research was conducted using in-depth interviews and lifelines. Data was collected in Poland and Croatia. Purposive sampling was used. Participants included 24 breast cancer patients undergoing treatment. The gathered data was analyzed through reflexive thematic analysis, supported by MAXQDA software.

Results: Breast cancer patients receive indisputable, contradictory, or well-intentioned yet harmful and oppressive educational messages which become memorable. These take the form of advice, recommendations, warnings, tips, and stories. Sources include medical staff, other patients and their relatives, and the media. Patients primarily expect these messages from doctors, whom they perceive as medical authorities and the main source of reliable knowledge. Furthermore, patients identify missing yet expected educational messages that also become memorable due to their absence. The demand for educational messages, as well as their sources and content, shifts throughout the cancer trajectory.

Conclusion: These results enrich the study of memorable messages by enhancing the understanding of the role of educational communication in informational support for cancer patients.

KEYWORDS: *cancer trajectory, education, lifelong learning, memorable message, patient*

1. INTRODUCTION

During the last decades, patients have been becoming responsible for decisions making regarding their health, disease self-management and self-care. This requires the patient to be active, and it is not possible without having appropriate knowledge and the ability to acquire new ones. The systematic review of the literature has confirmed that breast cancer patients, *with any culture and language, with any age group or country of residence in terms of level of development, prioritize their*

information needs in the field of diagnosis and treatment(1). At the same time, information and psychological needs are still the most unmet needs among women diagnosed with breast cancer(1-3). This problem may become more serious, given the systematic increase in the average life expectancy after diagnosis, the increase in the number of pa-

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tients struggling with disease recurrence, metastases or more advanced stages of cancer, and the increase in the number of younger women diagnosed with the disease. Each of these groups has even greater needs and expectations regarding health education(3), seeing it as an opportunity to better cope with the challenges of the health crisis on various levels, in line with the belief that greater knowledge creates the opportunity to better self-care and regain health or derive satisfaction from life despite illness. Healthcare providers have a significant role to play as learning facilitators(4), because they are perceived by patients as the most important source of reliable information and knowledge(5). At the same time, empirical studies have shown breast cancer patients often seek information and/or knowledge in variety other sources, including the internet(5,6), patients organizations and active patients sharing their experiences(1,4,7,8), press and (auto)pathographies(9). Furthermore, they learn based on their personal experience and biographies(7). Research has shown that knowledge about the disease and treatment procedures is a factor in the initial decision to seek medical care and continue it(10-12), attitudes towards the treatment(10-12), and following medical advice(13). However, the diversity of information and knowledge and their sources make cancer patients feel confused as learners(14).

From the pre-diagnostic period to the stage of monitoring the effects of oncological treatment, patients engage in numerous conversations about their illness. Some of them have an educational potential, even if the conversation is not conducted with the intention of teaching-learning. During these conversations, patients may receive messages that will be well remembered for a long time and have significance for the recipient's socialization, influencing their life and identity. These messages have been called memorable messages(15). According to Knapp, Stohl and Reardon, precursors of this concept, memorable message is characterized by memorability (i.e., message is remembered for extremely long periods of time), brevity and orality (i.e., a short and verbal message), subjectively major influence on the course of the recipient's life, personal focus and personal involvement (i.e., the message concerns topics or experiences that are significant or important to the person), applicability (i.e., it offers a hint on how to deal with a specific, often crisis, situation), re-

flection of values (i.e., attitudes to maintain social hierarchy), and the importance of the sender (i.e., the older and wiser sender, considered as a credible source)(15). Adopting these theoretical foundations, researchers initially focused on analyzing the structure, form, content and circumstances of receiving messages, as well as their impact on the recipient's behavior and values(16). Over time, this early model of memorable messages was recognized as *undertheorized*(17) and not encouraging *critically examining whose knowledge and systems (i.e., power) these messages reinforced, or exploring how harmful or marginalizing messages might be disrupted and replaced with more empowering alternative messages*(16). Researchers have increasingly considered memorable messages in a broader socio-cultural context, drawing attention to their conditioning by ideological and oppressive discourses, as well as their lack of adequacy and usefulness to changing circumstances, and even harmfulness(16,18-22).

The detailed analysis of research on memorable messages conducted over the last four decades led to the development of the assumptions of the Theory of Memorable Messages (ToMM) (16,21,22). According to the latest work(16), the authors of this theory assume that memorable messages are remembered for long periods of time, but their content and meaning can change over the course of a person's life through retrospectively assigning meanings to them, taking into account new experiences and new life perspectives. Memorable messages are valenced, but their value can be negotiated between the sender, the recipient, and simultaneously changes over time. The meaning of memorable messages is contextual (i.e., modified by both the cultural and situational contexts in which the message was received), influenced by both the relationship between the sender and receiver of the message and the modality (i.e., interpersonal or mediated). Memorable messages are part of socialization throughout the life course, which means they influence identities, beliefs, and behaviors. They can be disrupted, or meaningfully transformed, making room for new messages. Successive messages accumulate throughout life, and a person may continually return to them, retrospectively assigning them a different meaning than the one initially assigned. Therefore, some memorable messages are questioned and rejected, replaced by new ones, more relevant to changing circumstances.

This disruption can result in a reluctance to continue transmitting the message.

Prior studies have confirmed that the most common sources of memorable messages that received cancer patients were healthcare professionals, family members, friends, other patients, and media(19,21, see also 23-25). Memorable messages take verbal, non-verbal and absent form(21,22,26, see also 23-25). Many of them are supportive, informative, educational, empowering the sick person(19, see also 23, 25). On the other hand, some of them are unsupportive, unhelpful and harmful(18-21, see also 24,25). The primary aim of the study is to identify, reconstruct and analyze memorable messages which breast cancer patients recalled and considered as part of their education. Furthermore, the aim was to identify missing educational messages that patients wanted to receive but did not receive, and therefore they became memorable. The study aimed to answer the following questions:

1. Who sent memorable messages that were a source of education for breast cancer patients?
2. What was the content of memorable messages that were part of education of women coping with breast cancer? What did they learn from them?
3. What educational messages have not breast cancer patients received even though they would like to receive it, and therefore considered them as memorable messages?

2. METHODS

2.1. Data Collection

This paper is part of the larger qualitative research that was conducted in Poland and Croatia(14,23-25). Both countries have similar rates of breast cancer incidence. According to data from the Global Cancer Observatory(27), in 2022, 24,418 (0.065% of the population) new cases of breast cancer were noticed in Poland and 3,108 (0.076% of the population) in Croatia. This type of cancer has been the most frequently diagnosed in women for several years in both countries.

Biographical research was conducted. Data was collected through in-depth interviews and lifeline. Each interview included questions about

following areas: sociodemographic data, biographical experiences during the breast cancer trajectory, and communication within two main life contexts – formal oncological care and informal care networks, including family. Each interview began with an invitation to narrate about the breast cancer trajectory, starting from noticing worrying signs of the disease. Each participant was also asked to draw a lifeline containing key events in her illness trajectory (e.g., cancer diagnosis, surgery, disclosing the illness to her relatives), and tell about these events. In the next part of the interview, detailed questions were asked to deepen the interviewee's story, as well as questions previously prepared by the researchers. These questions focused primarily on communication between the patient and other people, with a particular focus on memorable messages. It is worth emphasizing that when women were invited to participate in the study, they were explained what memorable messages were.

The recruitment of study participants and data collection procedures were slightly different in both countries. In Poland, invitations to participate in the study were sent to several patient organizations and published on social media. The invitation included information about the purpose and planned course of the research, the research team (i.e. affiliations, assumptions of cooperation, experience and key competences in conducting research), compliance with ethical principles during the research, and the planned publication of the research results while maintaining the principles of confidentiality and anonymity. Most of the interviews were conducted face-to-face, but some were conducted online. All of them were conducted by EM in Polish. On the other hand, in Croatia all interviews were conducted by BV with the assistance of EM at the University Hospital for Tumors, Sestre milosrdnice University Hospital Center, within the Department of Oncoplastic Surgery. The University Hospital for Tumors performs the largest number of breast cancer surgeries in Croatia. Although based in Zagreb, women from all regions of the country come there for treatment. It is also one of the few centers providing complete oncological care, from surgery to all forms of (neo)adjuvant therapy. Thus, hospital patients who met the research sample selection criteria and were identified by medical staff as appropriate for their physical and mental condition

were invited to participate in the study. The invitation to participate in the study contained the same information as the invitation used in Poland, but was formulated orally and addressed directly to the potential study participants. The interviews were conducted in a private setting (such as the living room for patients or the hospital room when the patient was alone) ensuring a sense of intimacy and enabling compliance with the principle of confidentiality. The participants were interviewed in Croatian or, at the request of the interviewee, in English. All interviews were audio-recorded. They lasted between 50 minutes to 2 hours 15 minutes. Data collection was carried out from May to October 2024 in Poland, and from June to July 2024 in Croatia.

2.2. Participants

Purposive sampling was used, based on the following criteria: female, over the age of 18 years old, diagnosis of breast cancer no more than 5 years before the research, ongoing treatment for breast cancer. Twenty-four women diagnosed with breast cancer participated in the study, including 10 from Poland and 14 from Croatia. The participants ranged in age from 34 to 76 years, with a mean age of 52.6 years. Eighteen study participants had completed higher education, while the remaining participants had completed secondary education. Fifteen study participants were married, one was divorced, three were widows, three were in a cohabiting relationship, and two were single. All participants were still undergoing some phase of breast cancer treatment. However, due to the longer period of time after cancer diagnosis of the participants in Poland (approximately twenty months) compared to the participants in Croatia (approximately six months), the former have already completed many medical procedures, including surgical procedures. In Croatia, women who were in the perioperative stage of treatment took part – those undergoing segmentectomy, mastectomy, mastectomy with reconstruction, with axillary lymph node removal, or expander replacement. Some of them had previously received neoadjuvant chemotherapy.

2.3. Data analysis

The interviews were transcribed verbatim. The transcripts did not return to participants for

comment or correction. Transcripts of interviews conducted in Polish and Croatian have been translated into English.

Reflexive thematic analysis was used to analyze the data(28). Qualitative data analysis, including coding, analyzing and visualization of research content, was supported by MAXQDA software to ensure a systematic and rigorous process. Researcher triangulation was used. Two researchers (EM and BV) were involved in reflexive thematic analysis, starting it from familiarization with data and initial code generation. During these stages of analysis, the coders worked separately and individually on all transcripts, maintaining audit trails. Then, the researchers compared the results of the analysis. The initial codes which were not agreed upon by the coders, were analyzed and discussed again until consensus was reached. Then, further stages of reflexive thematic analysis (i.e., searching for themes, reviewing themes, and defining themes) were carried out. Finally, the thematic map which covers all themes and subthemes was developed and presented to the research team. The results were discussed by the whole research team. The research report includes illustrative quotes marked with the country abbreviation and the interview number. Findings were provided to study participants who indicated they wanted to receive them.

2.4. Ethics

The research project entitled '*Memorable messages' as part of communication in formal and informal caregiving for women with breast cancer* was approved by both the Research Ethics Committee of the University of Lodz, Poland (reference number: 11/V/2023-2024) and the Ethics Committee of Sesre milosrdnice University Hospital Center in Zagreb, Croatia (reference number: 003-06/24-03/031, Reg. No.: 251-29-11/3-24-03). All the participants were aware of their rights as study participants before expressing their consent to participate in the study. These rights encompassed the right to withdraw at any point without consequences, the right to refuse to answer any question, and the right to confidentiality and appropriate protection of their personal data. Written informed consents were obtained from all participants, and all participation was strictly voluntary and confidential. This study did not exceed the scope of the original ethics committees approvals.

3. RESULTS

As a result of the reflexive thematic analysis, three main themes were developed: educational messages as memorable messages; well-intention yet harmful and oppressive educational messages as memorable messages; missing expected educational messages as memorable messages. The first theme covers two subthemes: indisputable educational memorable messages, and contradictory educational memorable messages. All of these themes were connected to the learning experiences of the study participants. The thematic map is presented in Figure 1.

3.1. Educational messages as memorable messages

All participants expressed a need for learning in a health crisis, viewing knowledge as an opportunity to better cope with the challenges of treatment and its psychosomatic consequences. Knowledge was desired even by women who had some previous experience with cancer (e.g., their own illness several years ago, caring for sick husband) and possessed some knowledge of the treatment procedure, its effects, and opportunities for self-care during the illness. The study participants recalled many educational messages that became memorable for them. These comprise the theme of *educational messages as memorable messages*. It includes indisputable and contradictory educational memorable messages. The detailed thematic map for this theme and its subthemes is presented in Figure 2.

3.1.1. Indisputable educational memorable messages

An indisputable educational memorable message is a message that contains knowledge about the disease, treatment, and its effects, consistent with the biopsychosocial model of health. This knowledge provides informational support, enabling the patient to better prepare for subsequent stages of treatment and facilitating coping with the disease and its consequences across multiple dimensions: physical, mental, spiritual, social, and economic. The credibility of this message’s content is beyond question.

During the pre-diagnosis period, some study participants received indisputable educationally memorable messages from two sources: a doctor and the media. One participant was warned by her doctor about the risk of developing breast cancer after the age of 40 as a consequence of treatment for Hodgkin’s disease she underwent in adolescence (*The doctor told me there was a possibility that in my forties, I could develop breast cancer. Young girls who undergo radiotherapy at that age often get breast cancer later. [CR_9]*). This warning resulted in the participant adopting a healthy lifestyle, regularly participating in preventive screenings, and early tumor detection. In turn, this type of media-derived messages were included in stories about breast cancer survivors published in reports, requests for financial support for treatment, and educational campaigns during October—Breast Cancer Awareness Month. Three study participants were accidental recipients of these messages, meaning they did not intentionally seek them out. They addressed breast cancer prevention, the

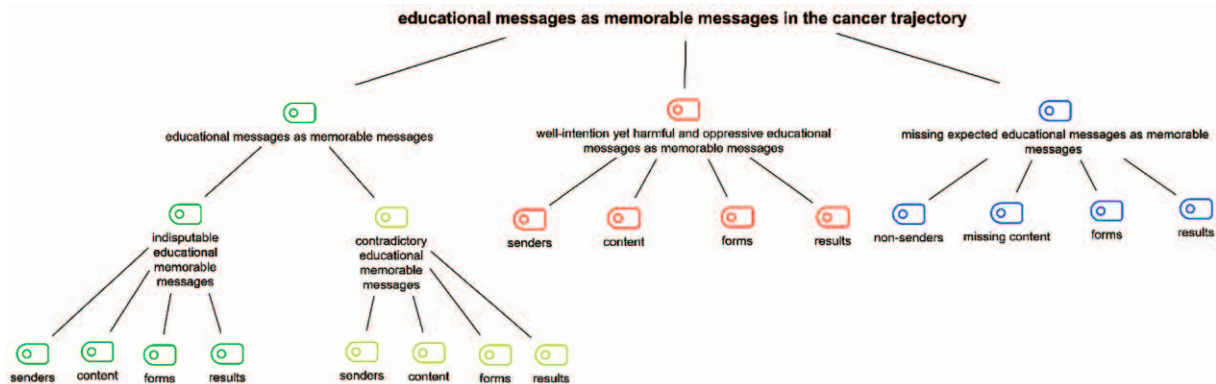


Figure 1. Thematic map prepared using MAXQDA software

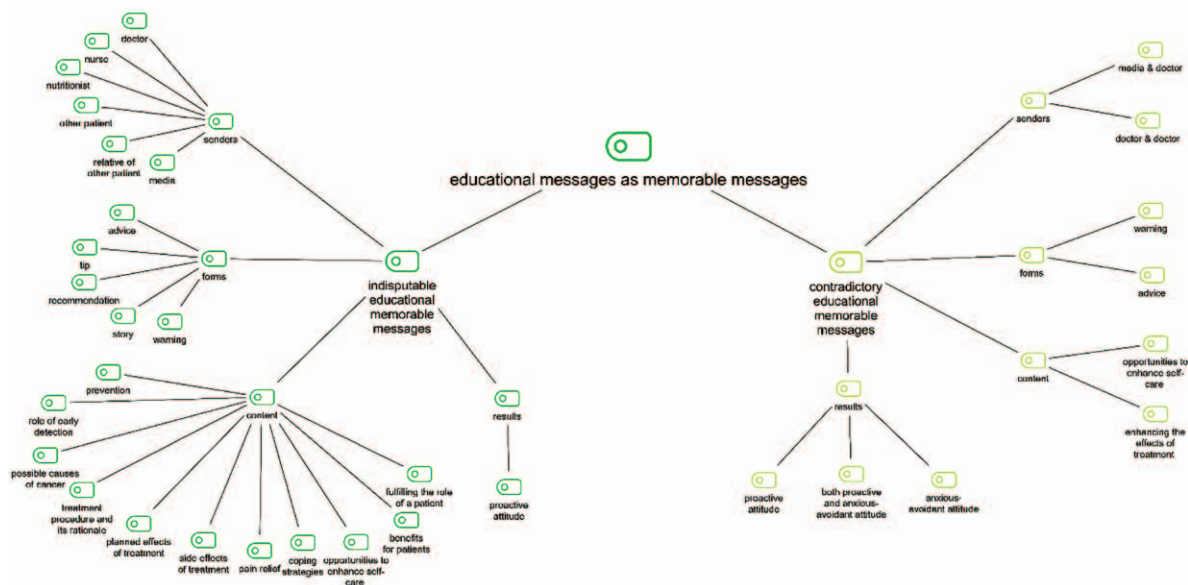


Figure 2. Thematic map of the theme ‘Educational messages as memorable messages’ prepared using MAXQDA software

importance of early detection, and patients’ struggles with the disease. As a result, the participants performed breast self-examinations or brought forward scheduled preventive screenings, which was also the beginning of their cancer trajectory. These messages may not have become memorable if not for their subsequent cancer diagnosis.

In turn, at the time of diagnosis and in the post-diagnostic period, doctors were the most frequent senders of indisputable educational memorable messages. The vast majority of such messages received from doctors concerned medical issues, including (possible) causes of cancer (e.g., ‘a gene mutation is the cause of the disease (...) You were still at such a young age, because women usually get sick after the age of 45, so you have changed the statistic.’ [PL_6]), ‘it’s possible that due to those hormones, cancer came’ [CR_7]), treatment procedure and its rationale (‘The entire breast will be removed because there are subtle lesions throughout the breast. The tumor appears to be diffuse.’ [PL_8], ‘The tumor is too large to be operated on. Chemotherapy is necessary to reduce it.’ [PL_10], The doctor said that I was young... that I might not want to do it, because the situation was different, because I was fighting. But later, when I would win (...) I would regret not doing it. [PL_8], ‘we will do chemotherapy first, so it will be easier for you to bear the surgery later’ [CR_6]), and both planned and side effects of the treatment (He said it wasn’t time to look yet, and he didn’t let me. He

held my head up. Said, ‘no looking’. [CR_4], when changing the dressing after breast reconstruction surgery], ‘it was a result of the chemotherapy. The therapy destroys the mucous membranes in the intestines and stomach, the entire digestive system, and apparently, it takes time for that to regenerate — a long time.’ [CR_8]). The study participants also recalled several messages focused on mental health (‘don’t look for cancer (...) You should pay attention to unusual pain, if it recurs in one place. (...) but not every pain means cancer.’ [PL_1], ‘Remember, you are not the only person who is sick. The whole family is sick with you.’ [PL_6]). Unlike messages received from doctors, the content of such messages from other members of the medical staff (i.e. nurses, nutritionists) focused on preparing the patient for the next stage of treatment (‘Before you start the chemo, prepare for it. (...) Buy yourself a scarf or two, or a turban. You know, your hair won’t fall out right away, but your hairstyle will change. You know, it’s very important for a woman to be prepared. (...) It’s better to be prepared than to be unpleasantly surprised.’ [PL_2]), opportunities to improve self-care during the treatment (‘take some vitamin D and drink nettle tea, because it’s good for hemoglobin’ [PL_2], ‘take B complex vitamins’ [CR_11]), and fulfilling the role of a patient (‘If someone cares, they will sit and wait in a queue [to see a doctor] even five hours.’ [PL_2]).

Other senders of indisputable educational messages in the post-diagnostic period were non-

specialists, i.e., other patients and patient relatives, sharing their own experiences. Most often, memorable messages took the form of advice, tips, and stories. These were valued by the study participants to a similar extent as those delivered by a physician. However, their content differed from the messages received from a physician. They concerned the course of the treatment (*'when they give you half a blue pill, call your husband and tell him it's starting'* [CR_1]), effects of the treatment (*She said, 'it's not gonna be so bad. You will be functional'. Because in my head, I thought I won't be able to move my arms at all. I kind of imagined that I would be like T-Rex.* [CR_1]), opportunities to enhance self-care, including pain relief (*'buy cooling gloves if you take white chemo'* [PL_2]), benefits for patients (*'apply for a pension, let them assign you a degree of disability'* [PL_6]), and emotional coping with cancer (*'Organize everything in your head. Be task-oriented. Don't overthink what will happen. Live day by day.'* [PL_2], *She told me that in the ward where she was, there were seven women who had breast cancer. (...) but each had a different treatment. (...) 'Don't compare, don't torture yourself.'* [PL_8]).

The study participants did not want to be passive patients, relying solely on healthcare providers. They wanted to make informed decisions in collaboration with their doctors. Through self-care, they wanted to increase their chances of survival and recovery. Therefore, they appreciated knowledge that could empower them in this regard. All indisputable educational memorable messages were part of the learning and led to a proactive attitude. Their results were as follows: breast self-examinations, expedite pre-diagnostic testing, early detection, willingness to undergo preventive genetic testing of study participants children, self-care, self-empowerment, better coping with emotions, avoiding or limiting searching for information from non-experts as a result of conscious decision and trust towards the doctor, and strengthening self-directed learning. The identified memorable messages are an element of health education and socialization into the role of competent, resourceful and responsible patients for their health. No significant differences between the experiences of Polish and Croatian women were identified within this subtheme.

3.1.2. Contradictory educational memorable messages

Contradictory educational memorable messages are messages received from two different sources, and the educational message they convey is inconsistent. The recipient perceives a discrepancy between them, which leads to confusion, doubts, verification of the knowledge, or abandonment of the search. These contradictory memorable messages originated from media and doctors, or from two doctors. They took the form of advice and recommendation.

Most study participants engaged in online research about breast cancer and its treatment. They found a wealth of information this way, which they then compared with the expertise of their physicians. In some cases, online advice was not confirmed by the physician, or the patient received different recommendation from the specialist than the advice previously obtained from the media. These constituted contradictory educational memorable messages. Some of them, although they might seem to be trivial, became significant and memorable for the patients (*I read that I should avoid sushi. (...) the oncologist told me, 'no, don't change anything about your diet. Have everything because your body is now in shock anyway. Don't change anything else that will make it more shocked.'* [CR_1], *I read, 'when you have a double mastectomy, you have to wear a bra for six months, a specialist bra for six months, day and night, constantly.' The doctor said, 'one month.'* [CR_1]). The second group of contradictory educational memorable messages were messages sent to the patient by two doctors and contained various recommendations (*'But what kind of hormone therapy? If you have hormone-dependent cancer, what kind of hormone therapy? What did they write here? (...) Radiotherapy is not really recommended in your case, and hormone therapy is even less so.'* [PL_2], *the oncologist said that they wouldn't add this drug to my treatment because they couldn't do it. I'd already started treatment, and they couldn't add medications during the treatment. (...) The geneticist said, 'this drug should be included in the first stage of the disease because you have this gene.'* [PL_6]). The contradictory messages sent by the two doctors were reconstructed only by study participants in Poland.

For a patient fighting to regain her health and save her life, a lack of consistency in communication is crucial, as following the wrong advice or recommendations can undermine self-care and

the effectiveness of treatment. Some women chose to actively seek and verify information. However, they sometimes experienced excessive information overload and complained about a lack of sufficient competence to assess the credibility of the acquired knowledge. However, the others withdrew from seeking information online, following the advice of their physician – a medical authority. In the case of the two participants in Poland who received contradictory messages from doctors, cited above, the knowledge they gained reinforced their belief that they were not receiving treatment adequate to their test results. One of them, in collaboration with her doctors, made decisions regarding the next stages of treatment to correct previous erroneous medical decisions [PL_2]. For the other, it was impossible, so she was left with no choice and had to accept the situation [PL_6].

3.2. Well-intention yet harmful and oppressive educational messages as memorable messages

Well-intention yet harmful and oppressive educational message is message that is sent with the intention of teaching the patient something, but (over time) it is perceived by the recipient as unhelpful or even harmful. Such a message is often unsolicited and unwanted. Sometimes the patient hears it unintentionally because she is among other patients who are discussing their struggles with the disease. Sometimes she receives it from other patients in person or on social media. These messages take the form of (unsolicited) advice, warnings, and stories. They are sent by other patients. The detailed thematic map for this theme and its subthemes is presented in Figure 3.

Although the study participants appreciated other patients sharing their experiences and viewed them as an opportunity to learn from the biographies of others, not all messages sent with the intention of educating were helpful. Their content focused on the challenges of coping with the disease and its treatment (*'some people can't get out of bed during red chemo'* [PL_2], *'after chemo, you can't function; you lie in a bed, vomit, and can't get to the bathroom'* [PL_4]). The patients viewed these messages as harmful because they increased anxiety and sometimes led to mental health crisis. The warnings they contained proved unfounded, and the advice sometimes was ineffective. The warnings, also contained in patients' stories, proved unfounded as treatment progressed. (*I was afraid to go to bed, because I thought I'd taken chemo and wondered if I'd get up in the morning. (...) But once I got to know my body and realized that I could go to bed and get up without any pain, I thought, 'Okay, [...], you'll live!'* [PL_2]). In turn, advice on what decision makes contributed to the patient's growing doubts and confusion (*When you speak to more people, you lose sight of, I don't know what to do now. So many people are doing different things, but what is the best thing for me?* [CR_1]). Observing one's own body during the treatment led to the conclusion that everyone responds to treatment differently, so there's no point in worrying ahead of time. This type of memorable message resulted in regret attitudes (doubts about the decisions which were made), anxious attitudes (disorientation, mental crisis), and proactive attitudes (self-directed learning), as well as both proactive and anxious attitudes (i.e., rejecting advice from non-experts, avoiding seeking information from non-experts).

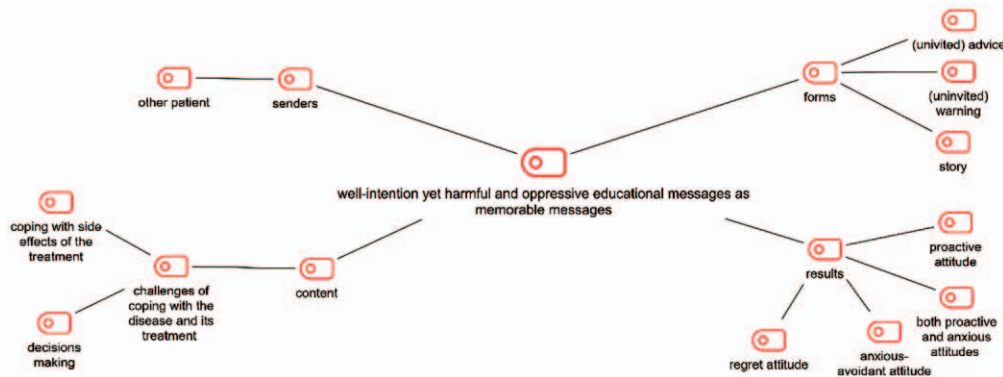


Figure 3. Thematic map of the theme 'Well-intention yet harmful and oppressive educational messages as memorable messages' prepared using MAXQDA software

3.3. Missing expected educational messages as memorable messages

A missing expected educational message is a message that a patient expects due to insufficient knowledge, but does not receive it. Patients expect knowledge and information primarily from specialists, whom they perceive as medical authorities and the primary source of reliable knowledge. Not receiving knowledge from others is not as significant as not receiving knowledge from specialists. This is likely why the only non-senders of educational messages that have become memorable are medical staff (i.e., doctors and nurses). An absent educational message is a failure to answer questions and provide explanations or information as a result of the unfounded assumption that the patient already knows or that the patient has no questions or concerns. Due to lack of experience, patients do not know what to ask. After some time, they realize that the lack of appropriate knowledge is a problem. It is worth emphasizing that the study participants understand the heavy workload of medical staff and the lack of sufficient time for each patient (*there are too many of us and too few of them* [CR_9]). At the same time, they emphasize the need for knowledge (*we want to know* [PL_3], *Tell me why. Tell me more.* [CR_1]).

The detailed thematic map for this theme and its subthemes is presented in Figure 4.

The content of missing educational messages varied, including possible causes of cancer (*I don't have the gene mutation. So I'm even more nervous because I consider, where did this cancer come from if I don't have the mutation? No one has explained this to me.* [PL_3]), risk level due to the diagnosis (*the oncologist told me that my levels are bad and I was already in the oncologist's office, so I knew that it was going to be bad. I just didn't know how bad.* [CR_1]), choosing a cancer treatment center (*'We will not perform this operation because you are too young, you have the gene mutation. You must find a hospital that would do it.'* What hurt me the most was that I didn't even get the name of the hospital. [PL_6]), rationale for treatment plan (*Why do people go to, I don't know, radiotherapy instead of chemo? What's the difference between the two? For me, it was very basic information I was missing.* [CR_1]), preparing for a conscious participation in subsequent stages of the treatment procedure (*He said he would be doing a biopsy. (...) I was waiting for some kind of anesthesia. It was like something from the Middle Ages. This huge needle. One held my legs, the other my arms, and they stuck it in my chest. (...) If I had known it was without anesthesia, I would have thanked them for it.* [PL_2],

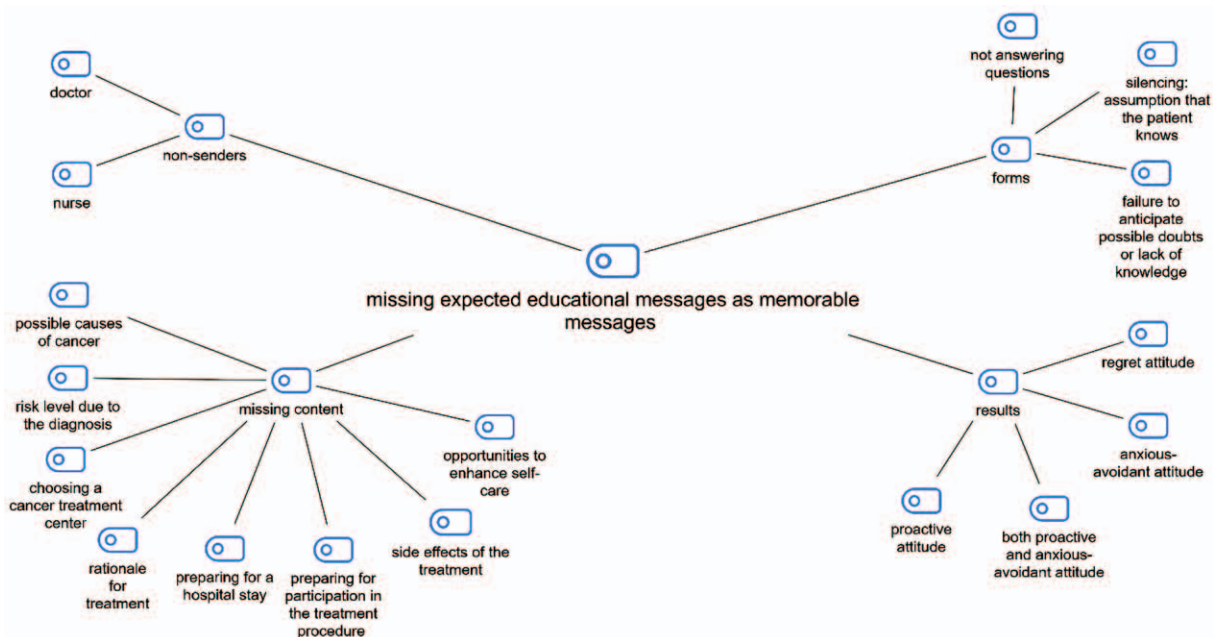


Figure 4. Thematic map of the theme 'Missing expected educational messages as memorable messages' prepared using MAX-QDA software

And I didn't know what the blue pill would do. She [the other patient] slept, I didn't sleep at all. And when I called my husband to tell him it's starting, I broke down, because now I'm like, shit, it's starting, and I don't know what's starting. I don't know what's going to happen. (...) 20 minutes the evening before, just to talk you through the process, would be great help for people like me. It wouldn't work for everyone probably, but it would really offer a little bit of, oh when this happens, it's normal. When they take you over in a different room, it's normal. When they tie your arms, it's normal. When you come out with white stuff around your face, but not everywhere, it's normal. It's normal. [CR_1]), preparing for a hospital stay and returning home after hospitalization (I was just like survival mode and operate, get it out, find out if I need chemotherapy or radiation or whatever and keep on fighting. I didn't think about how much it would hurt or little things like taking a towel to the hospital. I didn't bring a towel. (...) what to pack, what to prepare, what to prepare for home when you come home, like small little things [CR_1]), side effects of treatment and opportunities to enhance self-care (I took these cooling gloves, but (...) I didn't find out about it from the staff who administer the chemo, but from outsiders. [PL_2]).

The lack of desired knowledge and information burdened the study participants. Some of them regretted that insufficient knowledge deprived them of the opportunity to self-care according to their desires and abilities. They were also forced to make decisions based on incomplete data, which over time raised doubts about the correctness of the decision (e.g., choosing the size of silicone for reconstructed breasts) or triggered regret over a bad decision that could not be changed (e.g., choosing the hospital for surgery). Patients complained about limited self-empowerment due to insufficient provision of desired information. In some situations, unmet information needs also resulted in high levels of anxiety and even mental crises. Absent educational memorable messages also reduced trust in the doctor or the medical procedures. As a result, patients changed or avoided doctors who failed them, consulted with other healthcare providers, or consistently asked the same doctor multiple questions, sought knowledge and information from other sources, and used alternative medicine. It's worth emphasizing that their proactive approach to seeking knowledge sometimes coexisted with anxiety. Some pa-

tients asked doctors numerous questions, yet feared being labeled as irritating patients with whom doctors would be reluctant to engage. In still other situations, they actively sought knowledge outside the patient-doctor relationship. At the same time, they felt anxious about gathering information from non-specialists.

The empirical material collected during interviews in Poland and Croatia allowed for the identification of this subtheme in the data from both study groups. Nevertheless, two primary institutional and contextual disparities were observed. First, a higher frequency of reports concerning deficits in expected information or knowledge was noted among Polish study participants. Second, differences emerged regarding the systemic context of oncological care. In instances of informational gaps, Croatian patients demonstrated a higher degree of uncertainty regarding appropriate points of contact for medical inquiries compared to Polish patients. This issue was particularly pronounced during the initial stages of the disease, prior to the selection of a treatment center, or during chemotherapy overseen by multiple specialists. Despite these differences, participants from both countries identified online resources as their alternative source of information.

Insufficient information support also resulted in proposals for solutions to improve the healthcare system for cancer patients in terms of education and counseling. The study participants suggested that oncology hospitals should have nutrition center, counseling center, health education center, and psycho-oncological support as part of regular care. They also recommended providing patients with basic information on how to prepare for their hospital stay and return home after a specific stage of treatment. It would also be helpful to have a consultation with a healthcare provider just before the next stage of treatment (e.g., surgery), during which the entire procedure would be discussed. Even a short conversation can bring a lot of peace of mind. Study participants also stated that psychological support for doctors would be beneficial. Some of them, recognizing gaps in patient education, expressed their willingness to engage in patient outreach and share their knowledge through volunteering after treatment. However, some patients shared important tips with other patients during the treatment.

4. DISCUSSION

Breast cancer diagnosis disrupts a patient's life and compels them to take remedial action to understand and manage their situation. Knowledge is crucial for coping with both treatment and self-care challenges and regaining a sense of control. This study supports the findings of other research, which has demonstrated a link between a patient's efforts to understand and manage a new life situation and learning(4,6,7,29,30). Many learning theories are suitable for exploring learning in health crisis situations. They have provided the theoretical framework for numerous studies (4,7,29,30). The current study used the theory of memorable messages. Although not strictly a learning theory, it offers a new, previously unexplored way to identify patient learning during the cancer trajectory. Empirical data analysis suggests that both received educational messages and those that were expected but undelivered – which become memorable messages – are significant for breast cancer patients' learning. Memorable messages intended to educate patients fall into several categories: those that are indisputable and helpful, those that are contradictory and force a choice, and those that are harmful and oppressive.

The current study reflects the findings of other studies indicating that medical staff are facilitators of learning(4,7,9) and sources of memorable messages that are part of patient education(19, 21,23). Doctors are medical authorities, so patients value the knowledge they receive from them(5), and at the same time, they notice and remember situations in which they did not receive the expected knowledge. Therefore, educational memorable messages, or their absence in the doctor-patient relationship, foster trust in the doctor(23) or reduce or even lead to distrust(24). As the empirical material analyzed indicates, physicians are primarily a source of medical knowledge, closely related to test results, diagnosis, treatment procedures, and their effects. Other medical personnel (e.g., nurses, nutritionists) provide advice and guidance on how to better prepare for the next stages of treatment and how to take care of themselves during treatment. Furthermore, nurses, through educational memorable messages, socialize patients in their role as patients, advising them on how to function within the healthcare system, as well as on the norms established by other pa-

tients and the potential benefits of meeting them. The identified differences in the content of educational messages received from medical personnel may suggest that specialists complement each other in patient education.

However, patient education provided by medical staff is not sufficient, as indicated by the results of other studies conducted among cancer patients(1,30). Participants in this study identified gaps in the knowledge and information provided to them. Unmet information needs were significant enough to be remembered well and for a long time. Absent education, considered memorable, refers to possible causes of cancer, risk level due to the diagnosis, choosing a cancer treatment center, rationale for treatment procedure, preparing for a conscious participation in subsequent stages of the treatment procedure, preparing for a hospital stay, side effects of treatment, and opportunities to enhance self-care. The scarcity and simultaneous need for knowledge, along with open access to other sources, fosters independent pursuit of knowledge and self-directed learning. The medical staff's message is supplemented and reinforced by, among others, other oncology patients and their relatives, who, based on their own experiences, offer suggestions, advice, and warnings. These are practical tips that are highly valued by patients. It is worth noting that memorable messages from patients and their relatives are often hidden within the story of their struggle with cancer, or the entire story is treated as a memorable message. This finding is important given that narratives produce stronger cognitive and affective responses immediately, which may influence on behaviors and increase motivation to act(31). As an example, we can use stories about breast cancer survivors, which motivated the study participants to breast self-examination and participate in preventive tests. On the other hand, narratives make their recipients experience more positive and negative affect compared to provided only information – without any story(31). This could have led some participants to perceive such a message as unhelpful and harmful, as it caused an explosion of fear about what might happen (e.g. lymphedema management as a result of surgical treatment, nail loss after chemotherapy). Well-intentioned yet harmful and oppressive educational messages – usually hidden in stories – evoke fear, hopeless-

ness, or impose power on the patient, objectify her, and deprive her of her voice.

It is also worth noting that the media (mainly the Internet) as a source of educational memorable messages play a significant role in encouraging participation in preventive examinations. Their role is more significant than that of general practitioners. The media seem to be more active in preventive activities than medical personnel. This may be due to the heavy workload of physicians and a lack of time for patient education and encouraging preventive measures, or the greater ability of mainstream media to reach a wider audience. In turn, in the post-diagnostic period, the role of the media clearly weakens. Although patients look for knowledge and information on the Internet(5,6), the educational messages obtained there are less likely to be memorable. The findings are slightly different from the research by Smith et al(32), which indicates the media as the main source of memorable messages about breast cancer. Although educational memorable messages came from multiple senders in the current study, messages from medical staff, primarily physicians, were the most desired and highly rated due to their recognition of the physician's authority in the health field. The second most valued source of educational memorable messages were people with personal experience with cancer: patients and their family caregivers. Therefore, education provided by physicians and other specialists should become an important part of their work. The study participants suggested establishing educational and counseling centers for patients at hospitals, run by teams of specialists, including doctors, nurses, nutritionists, rehabilitation specialists, psycho-oncologists, and psycho-educators. Such activities are carried out in hospitals in Poland and Croatia, but they require intensification, especially in smaller medical centers and clinics in small towns.. Educational materials with practical advice on how to prepare for and navigate treatment can also be helpful. A noteworthy recommendation is to invite patients to create educational materials as a way to promote patient inclusion, increase their autonomy, and empowerment(33). In turn, such solutions can be complemented by education conducted by non-specialists based on their own experiences as volunteers or through cooperation between hospitals and patient organizations, which is already practiced in

both Poland and Croatia. Patients and their family caregivers education should be one of the priorities in healthcare systems, bearing in mind that it plays a significant role in shaping health-promoting behaviors and giving meaning to the disease, attitudes towards it and coping with health crisis, which ultimately leads to improved health outcomes(11,12,13). Improving patient knowledge promotes informed decision-making and satisfaction, adherence to medical recommendations, self-care, well-being, and better coping with the various challenges of oncological treatment(34). Systematic and comprehensive health education is also important because both healthy and sick persons increasingly expect personalized information on topics such as individual cancer risk assessment and individual prognosis after diagnosis or during treatment(30). Chatbots, which provide personalized and interactive educational support, can be helpful in this regard(35). However, they do not replace contact with specialists.

Comprehensive and complementary educational and counseling activities for patients may be particularly beneficial, given the contradictory, harmful, oppressive and absent educational messages reconstructed by breast cancer patients in the current study. Both knowledge gaps and unreliable information complicate preparation for treatment and participation in control tests and medical procedures, leading to increased anxiety and even emotional crises, feelings of confusion, and loneliness(29,30). In extreme cases, they can lead to serious negative consequences, such as abandoning treatment consistent with academic medicine and replacing it exclusively with alternative medicine.

The findings of this study suggest that knowledge and its deficits are most significant immediately after a breast cancer diagnosis and immediately before subsequent stages of planned treatment (i.e., surgery, chemotherapy, radiotherapy). The need for knowledge decreases during the cancer trajectory, which was also noted by other researchers(36). Nevertheless, knowledge is important for most patients throughout treatment and even after its completion. Cancer patients fear disease recurrence or cancer cell metastasis, so they exercise vigilance, and they consider physicians' downplaying or normalizing their reported symptoms as careless and undermining trust(24). A

cancer diagnosis is an emotional shock for most patients. Although emotions are an important component of learning, intense fear can be a barrier to seeking information and learning(4,29), which is consistent with our results. This may explain the withdrawal or avoidance of seeking information from non-professionals by some participants in our study, or the feeling of being overwhelmed and lost in the sheer volume of information they are acquiring(14). Overcoming fear is necessary to engage in self-directed learning, which in turn can help to understand what is happening and regaining control through self-care and self-determination(29). On the other hand, the lack of knowledge or information (especially from doctors) also causes an explosion of emotions and doubts. Woman diagnosed with breast cancer often feels lost and confused, which paradoxically results from a lack of sufficient knowledge to cope with the health crisis, and at the same time from the flood of information that reaches her from various sources. Information overload and the lack of sufficient competences to assess its credibility can be considered a shadow of lifelong learning(37).

Comparing the specificities of Poland and Croatia, it is worth highlighting the differences between the results obtained in the study groups. Polish study participants reported more absent educational messages that were considered as memorable than Croatian study participants. Furthermore, only Polish women recalled contradictory educational messages sent by two different doctors. This phenomenon may result from a higher prevalence of unmet information needs in the Polish study group or, alternatively, from a greater readiness to disclose such experiences due to the research setting (i.e., 'neutral ground' outside the clinical environment in Poland versus the hospital setting in Croatia). However, Croatian patients demonstrated a higher degree of uncertainty about what to do when faced with a knowledge gap. The Polish oncological system provides each patient with a dedicated coordinator who acts as a liaison between the patient and the medical team, facilitating the organization of diagnostics and the flow of documentation and information. Furthermore, the continuity of care in Poland is supported by the assignment of a leading physician and the activity of volunteer programs (breast

cancer survivors), which provide peer-to-peer education even in hospital wards. These systemic solutions likely mitigate uncertainty arising from information deficits. Despite these discrepancies, study participants from both countries identified online resources as their primary alternative information source in instances of perceived insufficiency in clinical communication or systemic healthcare failures.

4.1. Limitations

Despite the significant contribution of the current research to the advancement of knowledge regarding educational messages and the lack of expected educational messages as memorable messages in the cancer trajectory, the study has several limitations. The sampling process and interview procedure in both countries were slightly different. Therefore, the study participants in Poland had a longer duration of breast cancer treatment than those in Croatia, and therefore had more experience. They also received treatment at various medical centers, as the study was nationwide. Meanwhile, the Croatian study participants were patients at one of the leading oncology centers in the country, which enjoys a very good reputation among patients. This was the main reason for choosing this hospital for breast tumor removal. Although during the interviews, the patients also reconstructed their experiences gained in other hospitals, their current situation (i.e., hospitalization) helped focus their responses on the "here and now". The shorter period since diagnosis, the treatment (or part of the treatment) conducted at one of the leading oncology centers in Croatia, and the location of the interviews (a hospital in Croatia vs. cafes and homes in Poland) may have led Croatian women to be more reluctant to express critical observations, despite the researchers' assurances of confidentiality and anonymity. These disparities may have led to a more negative retrospection of Polish women than Croatian women. Further nationwide research in both countries could confirm or deny these assumptions.

5. CONCLUSION

A breast cancer diagnosis disrupts the life course, introducing chaos, confusion, and disori-

entation. Consequently, many patients view it as a biographical turning point that clearly divides their life into two parts: before and after the diagnosis(7). Such a breakthrough compels the individual to engage in biographical work, aimed at finding meaning to the crisis within the context of their life history and sense of identity(7,38). This biographical work is inherently linked to learning, which helps patients – at least to some degree – manage the chaos, regain control over their lives, and better navigate the numerous challenges of a health crisis(4,7). Medical staff increasingly expect patients to be prepared so they can make decisions about their health and consciously participate in the treatment process. It would be false to assume that all patients intentionally engage in learning. However, all receive a variety of messages that serve an educational purpose. Some of these messages become memorable.

The findings of this study indicate that breast cancer patients received many educational memorable messages, which can be divided into three categories: indisputable, contradictory, and well-intentioned yet harmful and oppressive. The first of them provide consistent, biopsychosocial knowledge about illness and treatment, offering informational support, enhancing coping with health crisis and self-care. Contradictory memorable messages, coming from two different sources (i.e., doctor and media, two different doctors), create confusion and lead some patients to verify information while others withdraw from seeking it due to overload or perceived incompetence. Both indisputable and contradictory educational messages are rated as helpful, although – especially the latter – they require taking a stance on them and sometimes making a choice between them. These messages take the form of advice, tips, recommendations, warnings, or stories. On the other hand, well-intentioned messages, though intended to educate, were often perceived as harmful or oppressive due to their unsolicited nature or negative impact. These messages, typically in the form of advice, warning or stories, resulted in diverse patient responses including regret, anxiety, resignation, feeling lost, but also proactive attitude.

The absence of expected knowledge or information also may be memorable message(see also 24). Missing expected educational messages represent a significant gap where patients' reliance

on medical authorities remains unfulfilled. Patients prioritize knowledge from specialists; therefore, the failure of doctors and nurses to provide explanations—often due to the unfounded assumption that patients already possess the necessary knowledge—becomes a profound *memorable absence*. This lack of information results in diminished self-empowerment, regret over irreversible medical decisions made with incomplete data, and increased anxiety or mental crises. Consequently, patients often experience reduced trust in healthcare providers, leading them to seek information from alternative sources or adopt hyper-vigilant questioning behaviors despite fears of being perceived as *irritating*. This informational void not only triggers a proactive yet anxious search for knowledge but also motivates some patients to propose systemic improvements or volunteer to provide the peer education they themselves lacked.

The demand for educational messages, as well as their sources and content, shifts throughout the cancer trajectory. The need for educational messages is most acute immediately following a cancer diagnosis and in anticipation of subsequent treatment stages. While this necessity gradually diminishes throughout the illness trajectory, it remains a significant requirement both during and after treatment completion. Women receive the most memorable messages about breast cancer as part of their preventative measures from the media. However, during the peri- and post-diagnostic periods, the number of memorable messages received from medical staff, as well as other patients and their relatives, increases. Educational messages received from physicians are the most desired and appreciated by patients. However, different sources of memorable messages promote diversity in terms of their content and forms of communication. The results of this research enrich the study of memorable messages by enhancing the understanding of the role of educational communication in informational support for breast cancer patients. Health education should be based on its teleological foundations on the integral vision of a person as *the ontic whole of the bios and psyche, the organic body and the spiritual life*(39, p. 137). Therefore, educational messages about cancer should also take into account this holistic vision of the human being.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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Sažetak

Reci mi zašto. Reci mi više. (Neizrečene) edukativne poruke kao pamtljive poruke tijekom onkološkog liječenja

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Uvod. Određene edukativne poruke primljene tijekom procesa liječenja onkološke bolesti mogu se dugotrajno pamtit i te značajno utjecati na ponašanje bolesnika, čime postaju pamtljive poruke.

Cilj. Identificirati, rekonstruirati i analizirati prisutne i neizrečene edukativne poruke koje bolesnice s rakom dojke doživljavaju kao pamtljive.

Metode i postupci. Provedeno je biografsko istraživanje primjenom dubinskih intervjua i konstruiranjem životnih linija. Podaci su prikupljeni u Poljskoj i Hrvatskoj. Korišten je namjerni uzorak, a sudjelovale su 24 bolesnice s rakom dojke u tijeku njihovog liječenja. Prikupljeni podaci analizirani su refleksivnom tematskom analizom uz podršku softvera MAXQDA.

Rezultati. Bolesnice s rakom dojke primaju pouzdane, proturječne te dobronamjerne, ali štetne i opresivne edukativne poruke koje postaju pamtljive. One se pojavljuju u obliku savjeta, preporuka, upozorenja, smjernica i narativa. Izvori tih poruka uključuju zdravstvene djelatnike, druge bolesnike i njihove bližnje te medije. Bolesnice prvenstveno očekuju edukativne poruke od liječnika, koje doživljavaju kao medicinske autoritete i glavni izvor pouzdanog znanja. Nadalje, prepoznaju i neizrečene, ali očekivane edukativne poruke koje zbog svoje odsutnosti također postaju pamtljive. Potreba za edukativnim porukama, kao i njihovi izvori i sadržaj, mijenjaju se tijekom procesa liječenja onkološke bolesti.

Zaključak. Dobiveni rezultati doprinose istraživanju pamtljivih poruka produbljujući razumijevanje uloge edukacije i komunikacije u informacijskoj potpori onkološkim bolesnicima.

KLJUČNE RIJEČI: *proces liječenja onkološke bolesti, edukacija, cjeloživotno učenje, pamtljive poruke, onkološki pacijent*