Understanding the Role of Facebook Support Groups in Information Exchange for Cancer Patients in Romania

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Abstract

The rise of support communities on social media platforms like Facebook has opened up new avenues for individuals dealing with cancer to connect, share information and find emotional support. This study aimed to explore how Facebook support groups in Romania contribute to the well-being of cancer patients by providing them with information and assistance. Through qualitative research methods and a multimodal discourse analysis of forms of communication we examined the exchange of information within four public and private Romanian cancer support groups on Facebook. Our findings indicate that although there is still some misinformation present these groups serve as platforms for sharing advice, alternative treatment options coping strategies, personal experiences and emotional support. This research emphasizes the significance of Facebook support groups for cancer patients in Romania but also the need to address misinformation while promoting evidence-based practices within these communities.

Keywords: Facebook support groups, cancer patients, Romania, information exchange, information quality, online communities

1. Introduction

The rise of media platforms has had an impact on how people communicate and gain knowledge. Facebook, one of the networks has not only changed personal communication but also how patients and caregivers access health related information and support. Online support groups have become sources of information, emotional support and encouragement for those affected by cancer. Cancer remains one of the leading causes of death resulting in 10 million lives lost in 2020 alone (WHO, 2022). It is estimated that there were 19.3 million cancer diagnoses that year (WHO, 2020). In the European Union around 2.7

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million individuals were diagnosed with cancer in 2020 with a 1.3 million losing their lives to the disease. Unless significant interventions are made it is projected that by 2035 the number of patients will increase by 24% making cancer the primary cause of death in the European Union (European Commission, 2021).

Romania faces public health challenges due to increasing incidence and mortality rates related to cancer (Ministry of Health the National Institute of Public Health, 2021). According to the data released by the International Agency for Research on Cancer (IARC) there were estimated that around 100,000 new cases of cancer and 54,500 cancer related deaths occurred in 2020. The observed types of cancer include colorectal, lung, breast, prostate and bladder cancers (WHO, 2021). The survival rates for cancers in Romania are notably lower compared to the rates in the European Union (OCDE, 2021).

The Romanian healthcare system faces challenges when it comes to providing access to cancer care particularly in rural areas where healthcare infrastructure is lacking proper development (OCDE, 2021). Moreover, limited access to newer cancer drugs and technologies due to budgetary restrictions compounds the hardship for patients and their families. Hence, the need for alternative sources of information and support is growing (OCDE, 2021).

Romania's healthcare infrastructure is a combination of public and private sector. The country operates a health insurance system that covers all employed individuals and their dependents. Funding for the healthcare system comes from sources including social security contributions, taxes and direct payments made by patients themselves (OCDE, 2021).

In terms of cancer treatment options in Romania there are public and private hospitals as well as clinics that offer different modalities such as surgery, chemotherapy and radiation therapy (National Oncology Program, 2002). However, there are regions, rural areas, with less advanced healthcare infrastructure, where access to these services may be limited. Additionally, due to budget constraints the availability of cancer drugs and technologies could also be restricted.

Regarding support services Romania has organizations and NGOs that offer resources and assistance for cancer patients and their families. These include counseling, financial aid and home care services (ECPC, 2023). However, the accessibility to these services may vary depending on the location as many of these organizations are located in urban areas.

In this situation cancer patients often turn to searches for online information likely because oncologists have limited time for each patient (Madge et al., 2023). In Romania cancer support groups on Facebook play an important role in connecting patients with cancer, their families and caregivers. These online communities provide a platform for sharing information, personal experiences, emotional support and facilitating communication among peers. This can help individuals navigate the complexities of cancer care and improve their well-being.

2. Background and Literature review

2.1. Exploring the Landscape of Online Cancer Support Groups

The emergence of online support groups for cancer patients and their relatives originated around the mid-1990s, marked by early instances like the Association of Cancer Online Resources (ACOR) mailing list. This was set up in 1995 by Gilles Frydman, a cancer patient and advocate, after his own diagnosis of kidney cancer in 1993 (Patient Power, 2023). Frydman recognized a need for resources for cancer patients and their families leading him to establish ACOR as a platform where people could connect and share their experiences.

Initially focused on kidney cancer patients ACOR now encompasses over 100 email lists that cover types of cancer and related topics. These email lists are moderated by volunteers who have personally experienced cancer or have been caregivers themselves. They provide a space where members can exchange information seek advice and receive support. In addition to facilitating discussions ACOR offers resources such as cancer libraries, clinical trial information and a directory of cancer support groups. Today ACOR remains a source of information, support and advocacy for individuals living with cancer and their loved ones.

There are pioneering online support groups, for cancer such as the Prostate Cancer Mailing List, which was established in 1993 (PCF, 2017) and the Breast Cancer Mailing List, which was founded in 1994 (Newman & Jackson 2009). These initiatives have allowed individuals affected by cancer to come exchange information and provide assistance to one another.

2.2. The Role and Influence of Online Support Groups for Cancer Patients and Their Caregivers

The internet and social media have significantly expanded the accessibility and range of cancer support groups. While several recent studies (Petrič et al., 2023; Çobaner et al., 2022; Parker Oliver et al. 2022; Ma et al., 2021; Kadravello et al., 2021; Liu et al., 2020; Petukhova et al., 2020; Mikal et al., 2020; Harkin et al., 2020) have primarily focused on the role of support groups they did not specifically explore the distinctive features and challenges faced by cancer patients in different countries.

Online support groups are increasingly recognized as a resource, for both cancer patients and their caregivers. They offer informational support help alleviate cancer related depression and trauma and facilitate connections.

The aim of this review is to examine the existing research on support groups for cancer with a specific emphasis on how they affect and assist patients and caregivers. We have analyzed studies investigating the utilization of these virtual support communities highlighting their advantages and possible limitations while also pinpointing areas that require investigation.

2.3. The Progression of Online Support Groups for Cancer Patients

2.3.1. Initial Studies on Computer-Mediated Support Groups (CMSGs)

Researchers like Weinberg et al. (1996) were among the first to explore the effectiveness of computer mediated support groups (CMSGs) for cancer patients. They found that patients who participated in CMSGs experienced improvements in their well-being and perceived social support compared to those who did not participate. These findings highlight the benefits of CMSGs in providing social support, which can contribute to the overall well-being of cancer patients.

2.3.2. Rise of Online Cancer Support Groups in the 2000s

Around twenty years ago studies conducted by Shaw et al. (2000) and Winzelberg et al. (2003) indicated that patients derive advantages from engaging in discussions within support groups. Shaw et al. (2000) examined the availability, structure and content of cancer support groups and concluded that these platforms offer participants emotional support, facilitate information exchange and foster a sense of community. Specifically, women diagnosed with breast cancer considered their experiences within computer mediated support groups as an invaluable source of assistance while navigating through their illness. The anonymity provided by these settings promoted participation and enabled communication that might have been difficult in face, to face interactions.

According to a study conducted by Winzelberg et al. (2003) they proposed that an online support group could play a role, in reducing depression, trauma and perceived stress related to breast cancer among women with breast carcinoma. The participants reported advantages and increased satisfaction from their involvement in the intervention. However, despite the merits of web-based social support groups, the authors noted that this mode of communication brings to the fore multiple ethical concerns requiring consideration.

2.4. Online Health Communities (OHCs) and Social Media in Cancer Care

2.4.1. Impact of OHCs on Health-Related Outcomes

Online health communities (OHCs) play a role in facilitating connections allowing users to interact with others who are going through similar experiences and expand their social networks (Petrič et al., 2023; Rueger et al., 2021). From an operational standpoint Petrič et al. (2023) suggest that OHCs should allocate resources and establish mechanisms for expert supervision of health-related topics on social platforms. This would help minimize the spread of wrong information among OHC members and visitors.

Using network theory as a framework, Rueger et al. (2021) demonstrated that advice received from individuals with similar primary concerns is more valued when seeking non-professional expertise. They noted that such advice, provided by community members with insights from various healthcare domains, allowing a merger of different "non-expert" skills, becomes even more valuable.

2.4.2. Informational Social Support and Misinformation in OHCs

One of the reasons why people turn to health communities is to improve their overall health. Liu et al. (2020) studied how value is created collaboratively in these communities and developed a framework based on the theory of needs. Survey data suggested that informational, emotional, self-esteem, and camaraderie reinforcements positively influenced participants' sense of belonging within web-based health groups, consequently impacting information exchange, accountability, response, and advocacy actions. However, Petukhova et al. (2020) highlighted that some groups may have unverified advice underscoring the importance of better regulation and oversight of online health information. In response to this issue Zhao et al. (2021) created a model for detecting health misinformation, on social media platforms with an accuracy rate of approximately 85%.

2.4.3. The Role of Social Media in Healthcare

For individuals who receive a cancer diagnosis social media plays a crucial role. Some patients find solace in using social media to cope with distress (Bender et al., 2021) while others rely on it as a source of health-related information (Odeniyi et al., 2022). According to researchers, young individuals facing cancer view social media as a tool to actively cultivate a sense of well-being or balance by sharing, seeking, or avoiding specific types of cancer-related content (Stage et al., 2020). It is expected that individuals utilize media platforms to showcase and communicate strategies for managing their illness focusing on positive and life affirming narratives rather than negative or disheartening portrayals of their condition.

2.5. Use of Social Media Platforms for Cancer Support

2.5.1. Facebook as a Platform for Online Cancer Support Groups

Research conducted by Çobaner & Bek (2022) and Mikal et al. (2020) explored the role of Facebook as a platform, for support groups catering specifically to breast cancer patients. Çobaner & Beks's (2022) study examined how Turkish breast cancer patients utilized these support groups highlighting the significance of empathy and shared personal experiences within these communities. On the side Mikal et al. (2020) explored whether connections on Facebook offer beneficial social support to breast cancer patients in light of changes in their healthcare circumstances. Their findings highlighted that the support received

through Facebook is sporadic and limited. Both studies emphasize the advantages of utilizing Facebook as a platform for cancer support groups but they come with a warning for patients relying solely on social media for support.

While Çobaner & Bek (2022) emphasized the importance of empathy and shared experiences in online support groups Mikal et al. (2020) revealed the limitations of relying on Facebook for support during cancer treatment. Together these studies underscore the significance of comprehending how cancer support groups on Facebook contribute to supporting cancer patients and the need for research to develop strategies for leveraging online platforms in cancer care.

2.5.2. The Impact of Online Support Groups on Patient Outcomes

Digital communities such as support groups have become resources for individuals battling cancer who seek information, emotional assistance and connections with others facing similar situations. These virtual communities provide a unique platform to address unmet needs particularly for those with limited resources or limited access to healthcare. Harkin et al. (2020) examined how different features and formats of online support environments influence perceived support among cancer patients by investigating their impact on outcomes.

According to their research online support groups can play a role, in fostering levels of interpersonal relationships and supportive interactions. When creating these support communities, it's important to consider factors such as anonymity, trustworthiness of the website and customization of conversations to establish secure environments. In the case of peer led groups it is advisable to provide guidelines on maintaining a positive atmosphere during online idea disagreements.

Furthermore Kadravello et al. (2021) conducted a study on the impact of support groups for women with breast cancer (MBC) specifically focusing on their unmet needs. Their findings indicate that while online support groups can address needs a comprehensive approach is necessary. It is crucial for healthcare professionals, policymakers and civil society to collaborate in order to meet the needs of MBC patients through a patient centered approach that involves disciplines and multi-organizational approach.

2.5.3. Addressing the Needs of Cancer Patients' Relatives and Caregivers

Relatives and caregivers of cancer patients are critical in providing support and care, yet their needs often go unmet. With the rise of online platforms, health communities, and support groups, it is imperative to understand caregivers' and relatives' information needs and experiences to develop custom communication strategies and interventions.

Online support groups play an important role in assisting caregivers or related cancer patients (Van Eenbergen et al., 2019; Ma et al., 2021; Parker Oliver et al., 2022; Lin et al., 2019).

In their research Van Eenbergen et al. (2019). Ma et al. (2021) investigated the types of information that caregivers and relatives of cancer patients seek through platforms. These studies emphasized the importance of addressing the information needs of caregivers and relatives within health communities well as providing suitable support and resources to enhance the quality of care promote well-being and alleviate caregiver strain.

Van Eenbergen et al. (2019) found that on a cancer website relatives primarily shared information and expressed emotions related to their own well-being. On the hand Ma et al. (2021) identified the categories of information sought by family members of cancer patients in online health communities as well as the motivations behind their search behavior. This study took into account how Chinese traditions influence the information needs of these relatives. Overall both studies underscored the significance of meeting caregivers and relative's information needs in order to improve care quality and overall well-being. These findings can be a resource for understanding their requirements while addressing aspects as well, as informational topics. The research confirmed that when dealing with the challenges of cancer family members of patients often turn to seeking information as a way to cope.

Lin et al. (2019) suggested the role of social media platforms and online support groups is crucial in addressing the needs of cancer caregivers. However, Parker Oliver et al. (2022) highlighted that online support groups for caregivers lacked support leading to levels of anxiety and depression among them.

Lin et al. (2019) investigated the reason caregivers engage in Facebook support groups dedicated to long term care. Found that the satisfaction hypothesis accurately explains their motivations. Using a mixed-methods approach, their study found that the utilization and satisfaction hypothesis provides a valid framework for understanding the motivations behind participation in these groups. Furthermore, they proposed a theoretical framework to assess the impact of these factors on the social identity of these groups, while also considering the moderating influences of extraversion, age, and educational history. The analysis revealed that self-exploration was the primary social identification-associated motivator for engagement, and the connection between these factors and social identification was influenced by extraversion, age, and educational background.

Lin et al.'s (2019) research contributes to our understanding of how social media platformsre utilized for cancer support. They examine the factors that motivate user engagement and the impact of discussions, on decision making. These studies provide insights into developing personalized communication strategies and interventions that can enhance the support offered to patients and caregivers through platforms like Facebook and other online health communities.

By comprehending the information needs, emotional support and drivers of engagement in communities we can devise communication strategies and interventions that improve the support provided to patients and caregivers. Further research should delve into the role of platforms in fulfilling the needs of caregivers and family members well as their potential to enhance care quality and overall well-being.

3. Objectives

With an increasing number of cancer patients and their families resorting to Facebook groups, forums, and other online platforms for accessing information and forming connections with those in similar situations, the role of these platforms is expanding. Despite growing research on the benefits of cancer support groups, studies specifically examining Facebook support groups for cancer patients in Romania are notably lacking. Additionally, multimodal discourse analysis, which analyzes the interplay of text, visuals, and interactions within online communities, hasn't been extensively used in the study of Facebook support groups. This study aims to bridge this gap by investigating the exchange of information in Facebook support groups for cancer patients in Romania.

The research objectives are as follows:

- To identify and categorize the types of information exchanged in Romanian Facebook cancer support groups, including medical information, treatment options, emotional support, personal experiences, and coping strategies.
- To evaluate the level of engagement among group members in terms of active participation, information sharing, and provision of emotional support to others.

4. Research Questions

RQ 1: What are the main categories of information exchanged in Facebook support groups for cancer patients in Romania, and how do they correlate with aspects such as medical information, treatment options, emotional support, personal experiences, and coping strategies?

RQ 2: How can engagement in these Facebook cancer support groups be assessed and quantified, particularly concerning active participation, information sharing, and emotional support provision?

Comprehending the dynamics of these groups and how they assist cancer patients in Romania could offer valuable insights to healthcare providers and policymakers aiming to enhance cancer care and outcomes.

5. Methods

5.1. Study Design

A qualitative research design was the foundation of this study, utilizing a multimodal discourse analysis framework as set forth by Kress & Van Leeuwen (2001). This framework proved valuable in exploring the intricate relationships between various forms of communication - text, images, videos, etc. - within the scope of Facebook support groups for cancer patients in Romania. Utilizing this method allowed us to gain a more comprehensive insight into the interactions and information exchange within these online platforms.

5.2. Data Collection

The dataset for this research was collected from four Facebook support groups tailored for cancer patients in Romania, spanning both public and private domains, as outlined in Table 1. The criteria for group selection stipulated that the groups must: (1) focus primarily on the exchange and support related to cancer, (2) use the Romanian language predominantly, and (3) comprise a minimum of 2,000 members. Consent was sought and granted from the group administrators to collect and analyze anonymized data.

A total of 1,653 entries were recorded, including 478 posts that initiated a conversation thread and an average of 11 responses per post.

Table 1: Information of Selected Facebook Support Groups

Group ID	Group Name (Anonymized)	Focus (Cancer Type or General)	Membership Size	Public/Private	Date of creation	Posts in three months
1	Group A	General Cancer Support	16.770	Private	8 years ago	1.301
2	Group B	General Cancer Support	4.631	Public	6 years ago	126
3	Group C	General Cancer Support	4.142	Private	5 years ago	79

	Group Name (Anonymized)	Focus (Cancer Type or General)	Membership Size	Public/Private	Date of creation	Posts in three months
4	Group D	Breast Cancer	2.833	Private	8 years ago	147

Over a period of three months (January-March 2023), designated for data collection, a diverse array of digital content was accumulated. This included posts, comments, shared images and videos, along with links. A specially crafted web scraping tool aided in the extraction of data, preserving its multimodal nature. Personal identifiers within the data were thoroughly removed to ensure participant anonymity and safeguard against potential breaches of privacy.

5.3. Data Analysis

The data collected underwent analysis through three distinct phases:

- **Textual analysis**: We employed an inductive thematic approach to examine the posts and comments, identifying recurring themes and discussion topics. This step involved careful examination of the language group members used when discussing subjects such as medical advice, treatment options, coping strategies, and personal experiences. Coding and categorization took place iteratively to accurately represent emerging themes.
- Interaction analysis: This step entailed assessing engagement patterns, response rates, and usage of emojis and reactions among group members. The goal was to glean insights into support and feedback mechanisms and understand how different communication modes, such as text, images, and videos, impacted engagement levels and the quality of information exchanged.

5.3.1. Identification and Categorization of Information

The analysis began with an in-depth exploration of the content shared within the Facebook cancer support groups. The textual content of posts and comments was thoroughly reviewed, enabling identification of recurring themes, common discussion topics, and the specific language used by group members. During this process, codes and categories were established to outline the different types of information shared within these groups.

5.3.2. Assessment of Member Engagement

After categorizing the types of information, we assessed member engagement within these groups. This included examining the frequency and nature of interactions between members, such as the number of posts, comments, likes, shares, and other reaction types. This analysis provided insights into the level of active participation, the degree of information sharing, and the manner in which emotional support was offered within these groups.

5.3.3. Integration of Textual and Visual Analysis

The multimodal discourse analysis also considered the role of visual elements like images, videos, and emojis, acknowledging their vital role in online communication. We conducted a separate but integrated analysis of visual content, giving particular attention to how these elements contributed to the overall discourse within the group.

5.3.4. Understanding Engagement Patterns

We delved into patterns of engagement within the groups, noting whether specific types of content or timing of posts encouraged more engagement among group members.

5.3.5. Iterative Analysis

The data analysis process was iterative, cycling back and forth between the data and our growing understanding of the discourse. This allowed for a progressively more focused analysis, deepening insights over time.

5.3.6. Final Interpretation

Upon completing the comprehensive multimodal discourse analysis, we synthesized the findings to draw significant conclusions about the role of Facebook support groups in facilitating information exchange among cancer patients in Romania.

Table 2 presents an example of coded data from the multimodal discourse analysis:

Table 2: Example of Coded Data from Multimodal Discourse Analysis

Post ID	Textual Content (Anonymized)	Image/Video Content	Theme(s) Identified	Interaction Metrics
1	"I'm just starting out, invasive breast carcinoma"	Photo of patient	Treatment Experience, Emotional Support	119 likes, 116 comments
2	"Can anyone recommend a good oncologist"	Not Applicable	Seeking Medical Advice	47 likes, 60 comments
3	"I have to start chemotherapy again "	Not Applicable	Personal Milestone, Emotional Support	11 likes, 91 comments
4	"Since I have cancer, I get terrible bruises when I hit myself"	Photo of patient's leg	Alternative Therapies, Information Exchange	6 likes, 14 comments
5	"Does anyone know how bone metastases manifest"	Not Applicable	Personal Experience, Seeking Support	20 likes, 46 comments

Note: The content in the tables has been anonymized to protect the privacy of the Facebook support group members. The actual data used in the analysis contains more specific information, but it was handled with care to maintain participant confidentiality.

5.4. Ethical Considerations

In order to ensure the ethical conduct of this study, we reached out to group administrators to obtain their consent. All the data collected for the study was anonymized to preserve the privacy of participants and adhere to the ethical research standards set by the Association of Internet Researchers (AoIR).

5.5. Trustworthiness

To establish the reliability of this study, we implemented various strategies as suggested by Lincoln and Guba (1985). We achieved credibility through triangulation, by incorporating multiple data sources (posts, comments, images, videos, etc.) and performing iterative thematic analysis. Dependability was accomplished through a comprehensive explanation of the research methodology and study context. Confirmability was guaranteed through an audit trail documenting the research steps and decision-making processes. We ensured transferability by providing a detailed description of the research context, participants, data collection, and analysis processes.

6. Results

This study analyzed information exchange in four Facebook support groups for cancer patients in Romania, utilizing a qualitative research design and multimodal discourse analysis.

Of the 1,653 posts documented, 26% included a photo, often depicting test results. Additionally, half of the initial posts consisted of patients seeking support by sharing experiences, while 42% requested medical guidance. Regarding the responses, 28% shared personal experiences, 37% expressed encouragement and prayers, and 35% provided medical recommendations. Among the medical advice given by peers, 76% were based on personal experiences, while 24% suggested alternative therapies not supported by evidence.

6.1. Thematic Analysis of Facebook Group Discussions

6.1.1. Seeking and Exchanging Medical Information

A recurring theme within the support groups' discussions is the seeking and exchange of medical information. Patients and caregivers often ask for advice concerning treatment options, side effects, and symptom management. They also delve into the procedure and documentation required for health insurance and disability pensions. Some members even share links to legal and official healthcare resources.

Example No. 1:

Author

"Good evening,

I am reaching out to you with a sincere request for information, as much as you can provide. My father, who is battling lung and prostate cancer, is currently undergoing radiotherapy, but due to financial constraints, he's forced to discontinue the treatments (my mother, who suffers from dementia, doesn't receive a pension, and my father's pension isn't enough to cover all expenses, not to mention the radiotherapy sessions at Sanador). We've been in contact with the oncologist, who provided a medical report to help us continue the radiotherapy sessions. We have several concerns and questions:

Where should we submit the necessary documentation?

What does the committee meeting involve?

How long does the approval process typically take?

I appreciate any assistance you can provide! Wishing you good health!"

Responses from Group Members (All reactions - likes, loves, etc.: 1414; 30 comments):

- "Good evening! I can provide some guidance. My father was diagnosed with cancer five months ago and underwent 28 sessions of radiotherapy at the Neolife Clinic, completely free of charge! All he needed to bring was his pension slip and health card. You can find their phone number online to make an appointment. Our radiotherapy doctor was Dr. X. Best of luck to you!";
- "If your father is insured, I'd suggest considering the Amethyst Oncology Clinic in Otopeni or the Saint Nectarie Oncology Clinic in Craiova. They both accept insurance.";
- "The oncologist can issue you a referral for an MRI when it's required.
 The note should include 'Monitor 2.' All oncology patients are given
 priority, and they'll schedule you quickly. Wishing you good health!";
- "Radiotherapy can also be conducted at Med Europa, where it's offered free of charge. For financial aid, you might need to approach the institution responsible for disbursing disability pensions and allowances. You should compile a file containing copies of all relevant medical documents, including the oncologist's report and the social investigation report from the town hall. After you submit these documents, there will be two commission reviews.";
- "Disability pensions should be sought for both individuals. The
 applications need to be submitted to Social Welfare. In Bucharest, the
 financial support is usually higher than in other cities. Wishing you
 good health and may God bless your entire family!";
- "Here's a link that might answer your other questions related to the commission: https://anpd.gov.ro/.../incadrarea-in-grad-si-tip-de.../. What I can advise is that the medical file is crucial. The commission will ask you a few questions and then decide on the classification based on criteria set out in the law. Visit this link: https://legislatie.just.ro/Public/DetaliiDocumentAfis/212549, for a list of required medical documents pertaining to your father's illness (and possibly for your mother's). This will help you prepare the application

properly so that you aren't turned away. If necessary, consult with the DGASPC and possibly send them a copy of the file by email in advance, so they can let you know if any additional medical documents are required. I did this when I was filing in another county, which saved us from making an unnecessary trip, especially with a patient who was not in the best condition to travel. Another crucial factor is what the oncologist has specified in the report: whether the patient is mobile/dependent or not."

6.1.2. Sharing Personal Experiences

A significant part of the discourse involves sharing personal experiences. This typically includes recounting individual cancer journeys from diagnosis, through treatment, to recovery. Often, these shared experiences are used to provide guidance or information to others going through similar situations.

Example No. 2:

Responses from group members:

- "I attended my first chemotherapy session this past Thursday. My
 oncologist advised me to brush my teeth thoroughly, rinse with baking
 soda or mouthwash, and drink at least three litres of water per day. I
 followed his advice, and thankfully, I was able to handle the treatment
 well. I weigh 54 kg and am 1.55 cm tall. We must win this battle!";
- "Good evening! My father lives in Bucharest. During his radiotherapy, he wasn't hospitalized. He visited the clinic daily.";
- "For us, it proved more efficient to consult directly with specialist oncologists, neurosurgeons, and thoracic surgeons than to spend hours, even days, waiting at the door. Today, on January 10, 2023, we arrived for radiotherapy and chemotherapy at 8:15 AM and didn't leave the hospital until 7:38 PM. Yesterday, January 9, 2023, we spent from 9:30 AM to 4:30 PM in the hospital for radiotherapy, tests, and consultations.":
- "Regrettably, I'm all too familiar with the waiting times. The reality is
 that all oncology departments are overcrowded. Yes, you may arrive in
 the morning, but you never know when you'll be able to leave.
 Personally, I've decided to stop fighting windmills. My energy is finite,
 and I need to dedicate it to what I can influence.";
- "My father underwent surgery for colon cancer at Floreasca Hospital. I confidently recommend Dr. Y.";
- "I received my radiotherapy at Med Europa. I feel quite well now!";
- "I had radiotherapy treatment on my bones, specifically my pelvis and hips. The procedure took about 7-8 minutes".

6.1.3. Extending Emotional Support and Solidarity

In addition to the practical information exchange, group members also offer emotional support to each other. They demonstrate empathy, send prayers, and offer good wishes, thereby nurturing a compassionate and supportive environment.

Example No. 3:

Emotional support from group members:

- "Wishing you health and strength! \(\lambda_{\text{"}} \);
- "May you have good health! \(\lambda_{\text{"}}; \)
- "God be with you!";
- "I hope for your good health and believe in your recovery.";
- "If you need more information, I will happily provide it. Don't lose hope!";
- "May God grant you the strength to persevere in this unimaginable struggle and maintain your health.";
- "To those undergoing trials and tribulations, may God fortify their faith and grant them victory! Amen."

6.1.4. Advocating Coping Strategies

A significant part of the discussion is centered on coping strategies, both medical and non-medical. This usually involves sharing treatment experiences, discussing ways to manage side effects, or providing advice on handling the emotional toll of a cancer diagnosis.

Example No. 4:

Responses from group members:

- "I also attempted using glycerin, but couldn't tolerate it; it's nauseating. Then I tried Anaftin spray, but the problem still persists.";
- "I'm on the verge of despair. I've become an experimenter. Someone
 advised me to get a germ and fungal analysis done to identify the issue.
 We'll try that and see. Even though I've tried everything, from
 allopathic to herbal treatments, there has been no reaction to
 anything.";
- "Dr. D. is my recommendation. I underwent surgery for the same issue as yours in 2012 and, thank God, I am doing well. I also followed a course of chemotherapy and radiotherapy at the Oncological Institute Clui.":
- "Dr. Z at Neolife is great at answering any questions. I've had three rounds of radiotherapy with him and all yielded perfect results (one month prior to surgery, one week of stereotactic radiation for a lung metastasis, and one week of radiotherapy for the iliac bone all resolved!) without any side effects like burns. He is a true professional".

6.1.5. Endorsing Alternative Therapies

It's worth noting that a significant number of group members discuss and advocate for alternative therapies, many of which are not supported by scientific evidence. These include natural remedies, dietary adjustments, and specific products purported to slow down tumor growth. This reflects the desperation some patients may feel when traditional treatment paths are blocked or perceived as inadequate.

Example No. 5:

Author

"Hello. I had an ovarian neoplasm that was operated on and treated with chemotherapy a few years ago. During a routine check-up, my CA125 marker was found to have increased to 120, and a CT scan revealed a nodular formation of 60/50 mm in the adrenal gland. The oncologist stated that I can't undergo oncological treatment due to my heart issues. I have been told to wait... Do you have any suggestions for what I can do in the meantime? Are there any herbal treatments I can try to prevent the tumor from growing? Thank you in advance."

Responses from group members (All reactions - likes, loves, etc.: 1212; 18 comments):

- "Seek the opinion of another oncologist, preferably in a larger city.
 Why were you advised to wait until your heart problems are resolved?
 The cancer will only continue to progress; it won't stop on its own.";
- "I doubt that any herbal remedies would work... Make an effort and consult another doctor; I would recommend a doctor from Cluj, from IOCN.":
- "Malignant cells thrive and multiply in an acidic environment (pH less than 7). If we can make the environment alkaline, the cells will not divide. This way, we can slow down tumor growth. This can be achieved with tribomechanically activated zeolite. It's worth trying.";
- "Megamin Active could be a viable option. It's approved by the Ministry of Health. Join the Megamin Activ group and register as a member, there you can find information and testimonials from those who already use it. Also, being a part of the group gives you substantial discounts on orders.";
- "https://www.facebook.com/.../permalink/1166881207305478/ Megamin Activ";
- "There are no treatments available, only surgery. The so-called "treatments" are actually immunity-boosting pills. Surgery is the only option. The "treatment" for immunity is beneficial when the cells start to mutate, not when a tumor has already formed.";
- "Discontinue the herbal treatments, they're not beneficial. Consult a reputable oncologist instead."

6.1.6. Navigating the Healthcare System

Members frequently discuss ways to navigate the healthcare system, which can be complex and often confusing. This includes sharing information about healthcare providers, clinics, insurance companies, disability benefits, and even offering contacts and procedures to expedite treatment (see **Example No 1**).

6.1.7. Diverse Levels of Engagement

There are varying levels of engagement among group members. Some members are highly active contributors, while others tend to observe or simply react to posts. Active members regularly share experiences, pose questions, and offer support, while less active members mostly read and react to posts without making considerable contributions.

6.1.8. Quality of Shared Information

The quality of information shared in the groups is inconsistent. While some posts are based on personal experience or anecdotal evidence, others include links to reliable sources or official websites. However, the existence of misinformation or misleading advice highlights the importance of critical evaluation of the shared information.

6.2. Role of Visual Elements

Visual elements, such as images, videos, and emojis, played a significant role in facilitating information exchange and emotional support within the groups. Images and videos were often used to illustrate personal experiences, medical procedures, or treatment outcomes, while emojis helped convey emotions, empathy, and encouragement among group members.

6.3. Impact on well-being and support networks

Participation in the Facebook cancer support groups appeared to have a positive impact on the well-being and support networks of cancer patients and their caregivers in Romania. Many group members expressed gratitude for the information and emotional support they received, which helped them feel less isolated and more empowered to make informed decisions about their cancer care.

Example No. 6:

Expressed gratitude (Posts authors replying to group members):

- "Good evening. Thank you very much for your answer.";
- "Thank you, good health to you too! ";
- "Thanks for the information";
- "Thanks a lot for the message! ";

• "Thanks a lot to everyone for the recommendations! We trully appreciate the support."

6.4. Challenges and barriers

Several challenges and barriers were highlighted in the information exchange within the support groups. These include language barriers, privacy concerns, and the digital divide. Some members found it difficult to comprehend complex medical terminology or effectively express their needs, while others were hesitant to divulge personal information due to privacy concerns. Moreover, restricted internet access and a lack of digital literacy in certain regions of Romania limited the participation of some individuals in these online support groups.

In conclusion, the findings of this study emphasize the significant role Facebook cancer support groups play in the lives of cancer patients and their families in Romania. These online communities serve as platforms for information exchange, emotional support, and personal connections, which can improve patients' well-being and support networks. However, the inconsistent quality of shared information and the challenges faced by some group members underline the need for healthcare professionals and support group organizers to engage in monitoring and guiding these online communities to ensure the dissemination of accurate and reliable information.

7. Discussion

This study presents valuable insights into how Facebook support groups are utilized by cancer patients and their families in Romania for exchanging information. The findings align with research on the importance of support groups while also shedding light on the specific features and challenges faced by Romanian cancer patients. These insights contribute to the existing literature on how online cancer support groups impact outcomes as discussed earlier in our literature review.

Our results demonstrate that online support groups provide a platform for cancer patients to access information about the disease, treatments, side effects and coping strategies from both peers and healthcare professionals. This finding is consistent with research conducted by Odeniyi et al. (2022) and Bender et al. (2021). Notably we observed a growing trend of stories shared on social media platforms highlighting important strategies for coping with illness.

In line with findings reported by Petrič et al. (2023) and Rueger et al. (2021) our research emphasizes the important role played by Online Health Communities (OHCs) in facilitating social interaction and expanding users' social networks. Additionally, we underscore the importance of expert oversight, within OHCs to address concerns related to the dissemination of low quality information. Consistent with Rueger et al. (2021) we have observed the significant value of advice from peers who share primary concerns, especially those who can combine knowledge from different healthcare sectors.

Our research supports the role of cancer patient support groups on Facebook in Romania aligning with Liu et al.'s (2020) study. We agree with the call for regulation and oversight of health information to address potential issues related to misinformation as discussed in Petukhova et al.'s (2020) research. Furthermore, we find promise in research by Zhao et al. (2021) that proposes health misinformation detection models as strategies for tackling these challenges.

Our studys insights also apply to the role of Facebook support groups in assisting caregivers and relatives of cancer patients. Our findings highlight the significance of understanding caregivers' specific information needs in order to develop tailored interventions as emphasized by recent studies (Van Eenbergen et al., 2019; Ma et al., 2021; Parker Oliver et al., 2022; Lin et al., 2019). Online support groups offer caregivers and relatives a platform to express their emotions, concerns and experiences ultimately reducing feelings of isolation, depression and anxiety.

Future studies can explore the kinds of information exchanged and their perceived value to understand the strengths and limitations of Facebook support groups, as resources for cancer patients and their families. Analyzing patterns and trends in information sharing can help develop interventions that cater to patients and caregivers needs while also allowing for comparisons across different countries and cultures. Furthermore, investigating how demographic factors, like age, gender, cancer type and disease stage impact the experience and benefits obtained from Facebook support groups can inform the development of interventions tailored to demographics.

7.1. Practical implications

The findings of this study have practical implications for administrators of support groups and healthcare professionals. By understanding the types of information shared, common concerns and communication patterns within these groups' administrators can develop strategies to create supportive environments. They can also identify any gaps in information or resources and also ensure that the needs of cancer patients and their families are adequately addressed within these groups.

Healthcare professionals can modify their communication approaches based on the information needs and preferences revealed in this study. They can customize materials provide consultations or create resources specifically tailored to address the concerns and questions raised within support groups. This will ultimately enhance the quality of care provided to cancer patients. Additionally, the insights from this study can guide the development of targeted interventions such as programs, peer support networks or online resources to assist patients in navigating their cancer journey.

Moreover, the knowledge gained from this research can contribute to training for healthcare professionals by providing them with an understanding of communication dynamics within online cancer support groups. This understanding will enable them to engage with patients and their families, in both offline and online settings while promoting a patient centered approach to care.

7.2. Strengths and limitations

This study possesses strengths that bolster the authenticity and relevance of its findings. By examining posts and comments from Facebook support groups we can gain valuable insights into the genuine experiences and patterns of information sharing among cancer patients and their support networks. This approach enables us to truly understand the experiential aspects of individuals dealing with cancer and their support systems.

Furthermore, this study aligns with existing research on cancer support groups reinforcing the consistency of our findings. However, it's important to acknowledge limitations. Our findings may not be applicable to support groups or social media platforms as each platform has its distinct features and user dynamics that can impact how information is exchanged. To gain an understanding future research should explore different platforms and contexts of support groups.

Moreover, the research was limited to a specific three-month timeframe during which the analysis was conducted. Online communities are known for their changing dynamics; therefore, our findings may not fully capture future behaviors. Conducting studies could offer insights into how information exchange evolves within Facebook support groups over time.

Additionally, we recognize the limitation of not including messages and other forms of communication between group members in our analysis. These interactions could provide insights into how information's shared and the dynamics of mutual support within these groups. In the future it would be valuable to investigate ways of capturing and studying the interactions that occur within these support groups. This would provide a understanding of their dynamics.

Although there are some limitations this research contributes to our knowledge about how Facebook support groups facilitate information exchange among cancer patients. It highlights the potential benefits and limitations of these groups and provide practical implications for support group administrators, healthcare professionals, and organizations involved in cancer care.

In conclusion, our findings enhance our understanding of how cancer patients and their families in Romania use Facebook support groups to exchange information. They provide insights into the strengths and limitations of these groups and offer practical implications for support group administrators and healthcare professionals. By leveraging the insights gained from this research, tailored interventions and communication strategies can be developed to better support cancer patients and their families through online support groups. Future

research should continue to explore the role of social media platforms in cancer support and address the limitations identified in this study.

8. Conclusions

This study reveals the dynamics of information exchange within Facebook support groups for cancer patients in Romania. The findings underscore the role played by these platforms in offering emotional and informational support as an addition to traditional resources, like healthcare providers and support organizations.

The exchange of information within these groups contributes to a virtual collection of knowledge including medical advice, treatment options, emotional support, practical guidance and personal experiences. This collective wealth of wisdom greatly influences the decision-making processes and overall strategies for managing health within these groups.

However, it is important to acknowledge that while support groups offer benefits, we must not overlook the importance of ensuring the credibility and reliability of the information shared. The presence of misinformation on these platforms can have serious consequences. Therefore, addressing this issue becomes a necessity. Additionally, we should consider challenges such as privacy concerns and communication barriers that may arise in these communities.

Despite the limitations of this study its findings provide insights into the role that Facebook support groups play in supporting cancer patients and their families in Romania. These insights offer information for healthcare providers, support organizations and policymakers by showcasing how these platforms can enhance care and strengthen support networks.

Furthermore, this research opens up possibilities for future exploration. It suggests the need for quantitative research to validate and build upon these current findings within Romania as well, as internationally. Future studies could benefit from employing research methods larger sample sizes or exploring timeframes.

Additionally, it is crucial to explore how the quality and trustworthiness of information shared impact the healthcare decisions made by users. This study serves as a starting point, in that direction aiming to inspire investigations into the role of social media in healthcare.

In conclusion, the findings of this study emphasize the importance of Facebook support groups as valuable sources of emotional and informational support for cancer patients in Romania. They highlight the need for careful consideration of information credibility, privacy, and communication barriers within these groups. By addressing these challenges, healthcare providers, support organizations, and policymakers can leverage the potential of social media platforms to enhance patient care, improve support networks, and ultimately improve the overall well-being of cancer patients and their families.

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