

Health information needs for complementary and alternative medicine in cancer care

A qualitative study among women affected by
cancer

Sandra Gärtner

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Supervisor: Miek Jong

Examinator: Katja Gillander Gådin

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Abstract

Background: One in four cancer patients use complementary and alternative medicine [CAM] in Sweden. Despite patients' interest and needs, there is limited quality-assured information about CAM available, driving the patients to seek outside of the state funded healthcare system for guidance. Even though health communication and health information are a fundamental part of public health there is little consensus on the methodologies used within the field to meet target group demands. *Aim:* To explore the needs of women affected by cancer for evidence-based health information about CAM and cancer. *Method:* Participants for this study were women affected by cancer that partook in health information lectures provided by Regional Cancer Centre [RCC] about CAM and cancer. Data was collected through qualitative research design using face-to-face individual interviews conducted both physically and online. Data analysis was done with an inductive approach using a qualitative content analysis method extracting meaning units from the transcribed interviews that aligned with the research aim. The meaning units were condensed into shorter versions that were labeled with a code, which in turn was grouped into sub-categories and categories. *Result:* Three overarching categories and six sub-categories were found. Health information needs for women affected by cancer for CAM and cancer was: To be empowered (category 1), Accessible and understandable information (category 2) and Communications with health care professionals (category 3). *Conclusion:* It is essential to understand health information needs of women affected by cancer to provide tailored messages that could meet the demand of the target group. If the information is presented in an accessible and understandable way it may empower women affected by cancer to make informed decisions about ways to support their health and help foster a safe communication about CAM with healthcare professionals.

Key words: Health communication, Empowerment, Evidence-based health information, Integrative oncology

Abstrakt

Svensk titel: Hälsorelaterade informationsbehov om komplementär och alternativ medicin inom cancervården – en kvalitativ studie med cancerberörda kvinnor

Bakgrund: En av fyra svenska cancerpatienter använder komplementär och alternativ medicin [KAM]. Trots patienters intresse och behov finns det begränsad kvalitetssäkrad information om KAM tillgänglig i Sverige, vilket driver patienter att söka information utanför det skattefinansierade sjukvårdssystemet. Även om hälsokommunikation och hälsoinformation är en grundläggande del av folkhälsoarbetet finns det lite konsensus i vilka metoder som ska användas för att möta målgruppens behov av information.

Syfte: Att utforska behoven av evidensbaserad hälsoinformation om KAM och cancer för cancerberörda kvinnor. **Metod:** Deltagare var cancerberörda kvinnor som deltog vid hälsoinformationsföreläsningar om KAM och cancer anordnade av Regionalt Cancercentrum [RCC]. Data samlades in med kvalitativ forskningsdesign genom individuella intervjuer som genomfördes både fysiskt och online. Dataanalys gjordes med ett induktivt tillvägagångssätt med hjälp av en kvalitativ innehållsanalysmetod. Meningsenheter från de transkriberade intervjuerna valdes ut som överensstämde med forskningssyftet. Meningsenheterna kondenserades och kodades, för att grupperas i underkategorier och kategorier. **Resultat:** Tre övergripande kategorier och sex underkategorier hittades. Behov av hälsoinformation om KAM och cancer för cancerberörda kvinnor var: Att få känna egenmakt (kategori 1), Tillgänglig och begriplig information (kategori 2) och Kommunikation med hälsosjukvårdspersonal (kategori 3). **Slutsats:** Det är viktigt att förstå vilka behov cancerberörda kvinnor har av information om KAM och cancer för att kunna tillhandahålla målgruppsanpassade budskap. Om informationen presenteras på ett tillgängligt och begripligt sätt kan det ge cancerberörda kvinnor möjlighet att fatta välgrundade beslut för att öka sitt välmående och hjälpa till att främja en trygg kommunikation om KAM med hälsosjukvårdspersonal.

Nyckelord: Hälsokommunikation, Empowerment, Evidensbaserad hälsoinformation, Integrativ onkologi

Table of contents

Introduction	5
Health communication	5
Health information.....	6
Complementary and alternative medicine	8
CAM and cancer	8
Public health policies	8
Study rationale.....	9
Aim	10
Method	10
Context	10
Population and sampling method	10
Data collection method	11
Data analysis method	12
Ethical consideration.....	12
Pre-understanding and reflexivity	13
Result.....	14
Discussion.....	19
Discussion of result.....	19
Discussion of method	21
Conclusion	24
Implications for further research	24
Implication for public health policies	24

Introduction

A significant number of Swedish cancer patients use complementary and alternative medicine [CAM] to relieve symptoms or increase quality of life before, during or after treatment (Wode, 2024). Despite this, there is a notable lack of quality-assured and evidence-based health information about CAM provided by the state funded healthcare system (SOU 2019:15). As a result, patients seek guidance from external sources such as their personal network or the internet (Wode et al. 2019), which may lack reliability and transparency (Delgado-López & Corrales-García, 2018; Ernst & Schmidt, 2002; Ng, Verhoeff, & Steen, 2023). Health communication and health information are important tools to address patient needs and support patients in the decision-making process though methodologies usually lack consensus (Folkhälso myndigheten [Fohm], 2018), making it hard to meet target group demands. This study explores health information needs about CAM and cancer to align health communication strategies with the patients' need for information.

Health communication

Health communication is sought as a fundamental part of public health. Despite its importance, there is little consensus in the methodologies and approaches used within the field and the definition of the term varies between authorities and countries. The European Centre for Disease Prevention and Control [ECDC] defines health communication as “the study and use of communication strategies to inform and influence individual and community decisions that enhance health” (Sixsmith et al., 2014). In the United States of America, the Centers for Disease Control and Prevention [CDC] describes health communication as “the art and technique of informing, influencing, and motivating individual, institutional, and public audiences about important health issues” (Bernhardt, 2004; Rimal & Lapinski, 2009). The World Health Organisation [WHO] on the other hand explains that health communication is “the use of communication strategies (e.g. interpersonal, digital and other media) to inform and influence decisions and actions to improve health” (WHO, 2021). In Sweden, health communication as a discipline grew in the 1980s when the HIV epidemic was on the rise (Jarlbro, 2010).

Though it was not until 2004 that a Swedish definition of the term was coined. In a report from Palm & Sandberg (2004) health communication was described as “planned communication initiatives from authorities or government-supported organisations aimed at achieving health benefits at both a community and individual level”. As presented, the definitions vary slightly from one another. While the CDC frames communication as a general tool for change without specifying either the sender or receiver, the definitions from the ECDC, Palm & Sandberg (2004) and WHO emphasise evidence-based communication strategies directed from authorities to the public. This conflict of definitions was highlighted in the latest report (Fohm, 2018) on health communication from the Swedish Public Health Agency. In the report, the lack of consensus and the somewhat restricted definitions from the ECDC and Palm & Sandberg are noted as insufficient to capture the complexity of the field. Consequently, many studies on health communication lack a theoretical foundation and offer few tangible results. The theories applied tend to be rooted in psychology and behavioural science rather than in communication theory itself. As the report from Fohm (2018, p.11) states, “...the field seems almost entirely stagnant”.

Health information

While health communication is the process of exchange between two parties, health information is the content being transferred. These terms are sometimes used interchangeably, yet they represent distinctly different things. Health communication is typically a symmetrical process, allowing for a dialogue and mutual understanding between parties. In contrast, the distribution of health information is often a one-way, asymmetrical procedure focusing on delivering facts without immediate feedback (Jarlbro, 2010). In the age of the internet and social media, health information may be either well-supported by research or lacking in evidence. They can aim to promote health but can just as easily convey contradictory messages. The liberalisation of the media market has shifted the power from the institutions to the people where anyone could become a publisher without proper training or knowledge. This shift in power has affected how health information is communicated (Fohm, 2018).

The supply of fake news or fake science undermines credible sources of science, making it hard for the consumer to assess what health information is valid and which is not. An example of this is the alleged health information that the MMR-vaccine for measles, mumps and rubella should cause autism in children, resulting in record levels of measles in 2018 because of vaccine hesitation (Hopf et al., 2019).

Health literacy

Health literacy refers to an individual's ability to understand and apply health information to improve their well-being (Barry, D'Eath & Sixsmith, 2013). It involves the capability to critically seek, evaluate and transform health information into actions that can promote health. Within public health, poor health literacy is seen as a barrier to healthcare improvement and healthcare professionals [HCP] need the skills to communicate health information in ways that are accessible and clear for their target group. Improving health literacy could be seen as an opportunity to empower communities through education (Fohm, 2018).

Health education

Another area closely interconnected to health communication, health information and health literacy is health education. Health education seeks to influence and change behaviours by increasing knowledge and health literacy through health communication and health information. Emphasis is usually on improving individual and community health using a health promoting self-help approach (WHO, 2021) that touches upon the "social, economic and environmental determinants of health" (WHO, 2012). Health education is commonly used in topic areas where a behaviour change is needed to protect or increase health such as substance abuse, obesity, physical activity or HIV (WHO, 2012). As with the field of health communication, health education too offers various definitions of the term and a lack of consensus. WHO (2012) argues that there is a unique and overlapping relationship between health education and other concepts of public health such as health promotion, health literacy and even empowerment. Differentiating them from each other is therefore problematic, especially since the terminologies are often used interchangeably.

Complementary and alternative medicine

CAM is an umbrella term that includes various types of holistic therapies such as herbal remedies, natural medicine, energy healing or therapies offered by traditional medical systems such as Ayurveda or Chinese medicine (Statens offentliga utredningar [SOU] 2019:28; Wode, 2024). These therapies are not typically presented within the regular framework of Swedish healthcare that is predominantly rooted in the pathogenic model of health (Åkerlind, 2005) and financed through taxation (Janlöt et al., 2023). Patients that wish to use CAM must seek outside of the state funded healthcare system and pay for their use through own recourses.

CAM and cancer

Studies show that at least one in four cancer patients in Sweden uses CAM (Källman et al., 2023; Wode et al. 2019). CAM use amongst cancer patients is more prevalent among women with higher education and income (Wode et al., 2019), a pattern that mirrors the international sociodemographic of CAM users (Kristoffersen, Norheim, A & Fønnebø, 2013; Molassiotis et al., 2005; Nissen et al, 2024). Why women with a strong sociodemographic background tend to use CAM more frequently than other groups might be because women in general use healthcare services more often than men. Women with higher levels of education are also inclined to have greater health literacy, empowering them to take ownership of their recovery process and make informed decisions about their health (Kristoffersen et al., 2013). Cancer patients use CAM primarily for health promoting reasons, rather than trying to treat the cancer itself. The patients seek to relieve symptoms of conventional cancer treatment and increase quality of life or health in general. Patients usually find health information about CAM through social media, the internet or in their personal network, but the majority would prefer to receive quality-assured information directly from HCP (Wode et al. 2019).

Public health policies

Since the early 2000s, WHO has worked globally with strategies regarding CAM to develop policies and regulatory frameworks to integrate CAM in the healthcare system in a safe and effective way.

This is seen as an important step to reach Agenda 2030 [A2030] Sustainable Development Goal [SDG] 3 and ensuring healthy lives for all on a global scale (WHO, 2019). On a national level, the Swedish public health policies are rooted in A2030 with the goal of promoting equal and good health for the Swedish population. Target area 8 in the public health policies aim for an equitable and health-promoting healthcare system, stemming directly from SDG 3 (Fohm, 2022a). Furthermore, target area 7 is built upon SDG 10: reduced inequalities, and SDG 16: peace, justice, and strong institutions and addresses topics of control, influence and participation. The aim is to reduce discrimination and enhance societal inclusion for individuals and groups, and a core indicator is trust in social institutions, including the healthcare system (Fohm, 2022b). Many cancer patients who use CAM often feel compelled to hide their use due to fear of not being understood or respected by healthcare providers. This lack of open communication may lead to feelings of discrimination and a loss of trust in the healthcare system (Adler & Fosket, 1999; Eng et al., 2003).

Study rationale

There is a significant proportion of patients using CAM (Horneber et al., 2012) and there is high interest among cancer patients who seek health-promoting alternatives before, during or after treatment (Wode, 2024). Despite patients' interest and needs, there is limited quality-assured information about CAM available in Sweden. The state funded digital platform 1177, "all of Sweden's gathering place for information and services within healthcare" (Ahlerup & Friedmann, 2022), does not provide comprehensive and coherent health information about CAM. Nor do they specify how patients or the public could navigate when choosing CAM methods (SOU 2019:15). Neither do authorities such as the Public Health Agency, the Swedish Health and Social Care Inspectorate or the National Board of Health and Welfare have information or advice on CAM use directed to the public (SOU 2019:15). However, there are many commercial initiatives from interest organisations, individual entrepreneurs and companies that offer information about CAM. Studies show that these sources lack transparency and evidence-based research (Delgado-López & Corrales-García, 2018; Ernst & Schmidt, 2002; Ng, Verhoeff, & Steen, 2023).

This makes it difficult for cancer patients to evaluate information and navigate in CAM therapies in a safe way, which could lead to CAM causing negative interactions with regular cancer treatment and harm the health of cancer patients. Improving health literacy and supporting this group in navigating the vast amount of health information about CAM available online is therefore needed (Kristoffersen et al., 2022). In 2017, the Swedish government conducted an inquiry to increase patient influence and patient safety regarding CAM use. To reach this, the inquiry proposed an improved communication about CAM through increased knowledge about CAM for HCP as well as access to objective and evidence-based health information about CAM for the public (SOU 2019:15).

Aim

The aim of this study is to explore the health information needs of women affected by cancer regarding evidence-based health information about CAM and cancer.

Method

Context

Regional Cancer Centre (Regionalt Cancercentrum [RCC]) Stockholm Gotland is a Swedish knowledge agency acting as part of Region Stockholm. Their work lays in developing, improving and streamlining the cancer care in Sweden, both on a national and regional level. To meet cancer patients' needs for health information about CAM, RCC (Wode, 2024) has developed educational lectures about CAM and cancer with the goal of increasing both health care professionals and cancer patients' knowledge about CAM (Wode, 2024). During 2024 and 2025, RCC on behalf of Karolinska Institutet [KI], a Swedish medical university, was evaluating their forementioned lectures for people affected by cancer, which the work in this thesis was part of.

Population and sampling method

Participants for this study are women affected by cancer that were recruited during three health information lectures provided by RCC about CAM and cancer.

In these lectures, general concepts of CAM were explained, examples of evidence-based CAM were presented and tools for evidence-based information seeking were demonstrated (Personal communication, 25th October 2024). The lectures were conducted in October and November of 2024. The first lecture was held in person at "The House of Power" ("Kraftens hus"), a meeting point for people affected by cancer (Kraftens hus Stockholm, u.å). The second and third lecture were held online, one together with Amazona, a Swedish breast cancer association (Bröstcancerföreningen Amazona Stockholm, 2017), and the other together with Region Dalarna and the council for patients and families (Bergfors, 2024). The participants were informed about the study both verbally and in written. The participants were selected through purposeful sampling (Henricson & Billhult, 2017) and the criteria for selection was the participation in one of the above-mentioned health information lectures.

Data collection method

A qualitative research design using face-to-face individual interviews were chosen as data collection method (Henricson & Billhult, 2017). The method was chosen since the study aim to explore the personal experiences and subjective reflections of women affected by cancer and their needs for health information about CAM and cancer. The interviews were held in Swedish, one was conducted in person and the others through the online digital platforms Microsoft Teams and Zoom. The interviews lasted for approximately 30 minutes and were recorded using a dictaphone for secure data management. The author was following a semi-structured interview guide (Appendix 1 & 2) created by a senior researcher from RCC and KI. The participants were asked 13 questions about the health information lectures such as their expectations of the lectures, what knowledge they gained from the lectures and were encouraged to reflect about what was satisfactory and what could be improved to meet their needs. After the interviews the author wrote down personal thoughts and reflection that could be useful for the data analysis in a separate document. The interviews were transcribed using the Dictate functionality in Microsoft Word software and proofread by the author where latent messages such as long pauses, hand gestures or irony was added in the transcriptions with

square brackets. When storing the data, the author renamed the participants in a codebook using pseudonyms.

Data analysis method

The analysis was done with an inductive approach following Hällgren Graneheim, Lindgren & Lundman (2023) method for qualitative data analysis. The author read the transcribed interviews multiple times before extracting meaning units into Microsoft Excel that were aligning with the research aim. Every time the author worked with the analysis a new tab was created with duplicated content from the day before and renamed with the date at the time. This allowed the author to follow the progress over time and backtrack the analysis if necessary. The meaning units were condensed into shorter versions, only keeping the essential content and meaning. The condensed meaning units were thereafter labelled with a code, which in turn was grouped into sub-categories and categories. For every subcategory, meaning units were selected to highlight the message of the subcategory. If the meaning units were too long, ellipses (...) were used to clarify where text was removed. The chosen meaning units, subcategories and categories were discussed with a senior researcher from RCC, a supervisor from the Mid Sweden University [MIUN] as well as peer-reviewed during a midterm seminar. After the midterm seminar the aim was slightly reformulated to have more focus on the target groups needs for health information about CAM rather than evaluating the health information lectures as such. The sub-categories and categories were thereafter altered to align with the new aim and a preliminary theme was removed in its entirety. When presenting the result, the meaning units were translated from Swedish to English to ensure coherency with the overall study.

Ethical consideration

This study included participants in vulnerable situations due to their connection to cancer and the subject of CAM. Because of the nature of the participants and the possible sensitive information that could arise during the interviews the study was reviewed by the Swedish Ethical Review Authority and approved (registration number 2024-04426-01) prior to data collection.

In compliance with ethical requirements for information and consent, the participants received information about the study beforehand and were asked about consent both in writing and verbally. The participation in the study was voluntary and participants had the option to withdraw at any stage of the process. Interview data was anonymised and stored confidentially using pseudonyms in Microsoft SharePoint, protected with Two-Factor Authentication. The following names in the report are fake and the informants could only be identified using the established codebook.

Pre-understanding and reflexivity

The author had previous knowledge about CAM before the start of this study. Through personal experiences with the use of CAM-therapies for health promotion, an interest in whole-person health and a previous internship with RCC working with questions about CAM in the healthcare system, the author recognised the importance of ongoing self-reflection to minimise bias. The pre-understanding about CAM gives the author both possible advantages and disadvantages when conducting the research. Knowing about different CAM-therapies and the sensitivity regarding the subject, gives the author the capability to understand and meet the participants with empathy and informed questions. Instead of clarifying what CAM and CAM-therapies are during the interviews, the researcher could concentrate on understanding the participants personal experiences, unique perspectives and latent messages. This preunderstanding helped the author when building connection with the participants endorsing a safe and trusting conversation, as well as when analysing the qualitative data. In contrast, prior knowledge of CAM and a belief in whole-person health could increase the risk of interpretation bias and selective attention, as the holistic approach often associated with these topics might influence the analysis. Additionally, the researcher's personal connection to RCC could make it difficult to the critically observe RCC's working regime. Due to the nature of qualitative method as a study design, where the researcher plays an active role in the data collection, a natural influence of the research might occur (Henricson & Billhult, 2017). Consequently, continuous peer reviewing and mentoring by senior researchers was conducted consistently during the research process.

Result

Four women who had partaken during a health information lecture about CAM and cancer provided by RCC and had or had had a cancer diagnose at the time of the interview participated in the study. All of them lived in Sweden; one in a smaller city and three in a suburban area outside a bigger city. Age and type of cancer diagnose was not addressed during data collection. During the data analysis three overarching categories and six sub-categories were identified. The following section summarises each category and sub-category in detail, supported by selected quotes.

Table 1.

Overview of results from data analysis

Category	Sub-category	Example of supporting quotes
To feel empowered	Be heard and seen	“...I feel that you have my back in a sort of way...” [Miriam]
	Normalise CAM use	“...I really liked that the lecture, it normalises [CAM] in some way, and you don't have too many opinions of what is good or not...” [Beata]
Accessible and understandable health information	Audience tailored information	“...not everyone is an academic... researchers put the bar for information on too high of a level...” [Karin]
	Information dissemination	“...it's hard to digest it all at once ... you could split it up... part one two three or something like that...” [Beata]
Communication with HCP	An open dialogue	“I think it [the dialogue] is non-existent and I think it's mocking, they don't take this seriously...” [Johanna]

Increased knowledge about CAM	"...the healthcare system is not interested in a holistic view of humans unfortunately and that is needed to work with these questions..." [Karin]
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To be empowered

Being heard and seen. A need for women affected by cancer that emerged through the data analysis could be interpreted as the need to feel empowered. Often, these women were scared to speak about their CAM use in fear of being ridiculed. Nor were they used to HCP possessing the knowledge to adequately answering their questions without judgement. The need of being heard and seen was expressed both directly and indirectly by the participants. The participants spoke with gratitude that their questions were being recognised and answered by the lecturer. One participant shared:

"...it is so important to be heard, and I feel that you did that...you really tried to answer all our questions..." [Johanna]

Though this need of being heard and seen was also voiced more latently. To be heard and seen was a confirmation that what they are doing and feeling when using CAM is real, even if they're not believed by other HCP. One participant said:

"Confirmations of what I'm already doing and it's nice to know that even if the healthcare providers don't always agree all the time, but I know um that what I'm doing is helping me and now I have proof of that..." [Miriam]

Normalise CAM use. One of the participants described CAM as something controversial. Therefore, she and other participants expressed the values of receiving objective evidence-based health information about CAM and feeling grateful that bigger institutions are interested in this topic. Being presented with evidence-based CAM acts like a reassurance.

“...research wise, there is evidence even though it is not much but she [the lecturer] did actually show that there is evidence for this...”
[Beata]

The normalisation of CAM use together with the need of being heard and seen seem to comfort and assure the participants. To be heard and seen is about being recognised and respected whereas the normalisation of CAM as a field of science and CAM-use in general addresses the preconception that this group often meet. Both are interpreted as strengthening tools of empowerment.

Accessible and understandable health information

Audience tailored information. All the participants expressed a feeling of gratitude towards receiving evidence-based health information about CAM. Though they also emphasised that there is an importance of presenting this type of information in a way that is understandable for this target group. One participant shared:

“...there was some frustration among these who didn’t get uhm, they projected it on the fact that the slides were unclear but that doesn’t really matter but ...it can become a huge thing... how to say this, one can feel belittled of one doesn’t understand the slides.” [Karin]

People affected by cancer that are undergoing treatment are usually tired of the wealth of new information and impressions. Some do not have an academic degree, but even those who have could find it difficult to understand information that is too academic. The participants express the need for easily understood and audience tailored information that is not too academic with less text on each slide and are written in their mother tongue Swedish.

Information dissemination. There are differing opinions of how health information about CAM and cancer should be disseminated. One participant would like to receive the information through an online lecture, another through a physical lecture, a third from a prerecorded lecture and a fourth from tangible workshops. What they have in common is their eagerness to have more accessible information about CAM available.

Two participants suggested that it could be presented in a lecture series, with multiple lectures touching upon different areas of CAM and cancer. Since the participants have a lot of unanswered questions about CAM, like possible interaction with conventional treatment, if CAM can affect other symptoms such as those from menopause or which CAM-therapist to use, the need for more information is great. As one participant shared:

“...what you are doing is really important and it has to do with health, future and foremost the mental wellbeing for those suffering from illness... the project that you have now in all its different dimensions is incredibly important so please feel free to share what you conclude with us, email us the information.” [Johanna]

To receive health information is important for the participants though it is hard to understand evidence-based information that is too academic, which can in some ways feel belittling. The participants are not unanimous in how health information should be disseminated but have a need for accessible and understandable information that could help them navigate in CAM.

Communication with HCP

An open dialogue. The participants voiced much frustration regarding the communication about CAM with HCP but confirmed that the lectured gave them assurance in having an open dialogue about CAM with healthcare providers. One participant shared:

“...one should never be afraid of asking ones, that is what I think is the key message, asking one's doctor or one's healthcare professional. That is one's right to do...” [Karin]

“Having a dialogue with healthcare providers” [Beata] is something that is needed for the participants. Many have not shared their CAM use due to shame or being met with disrespect and there is a wish to get support through conversations.

“...it's about power dynamics too, which is about the fact that it's easy to talk to an empathetic doctor or healthcare professionals and that they, even if they don't have the knowledge, listens to what the patient says and maybe can kindly say: I don't know anything about these natural medicines, but I can find out about it. And then there is

another, the other tradition, where the doctor he knows best and the patient shouldn't come here with mysterious things because that is not scientific, stop that. And then it is difficult to do anything about such a person." [Karin]

Due to this unbalanced power dynamic, the participants feel they need to be very knowledgeable themselves since they need to fight for their cause. But sometimes they don't know how to do that. "How should I prepare myself for my oncology visit?..." [Miriam] is something that the participants need more support with. Especially since many of them are tired due to treatment and feel a sense of hopelessness when they are not being listened to.

Increased knowledge about CAM. To have this open dialogue with HCP, the participants would wish for an increased knowledge of CAM within the entire healthcare system. "...it's important that conventional medicine knows this too..." [Miriam] stated the participants and emphasised that there is a noticeable knowledge gap regarding CAM and cancer. As one participant shared:

"...if they could've given me more information on how I could've supported myself in this, and here are these options, try this. Now I had to do the work all by myself so I must have missed a lot of things that I probably could have done much better thanks to them not giving me information." [Johanna]

The lack of knowledge from HCP pushes the patients elsewhere for support when they would have liked to be supported by HCP. This elevates a feeling of powerlessness.

"...I feel that I had to be the contact centre myself and take responsibility for my own health to such an extent that if I had been sicker than I would have been completely powerless..." [Johanna].

To be able have an open dialogue about CAM the participants had a need for increased knowledge of CAM amongst HCP, as well as amongst the women affected by cancer themselves.

Discussion

Discussion of result

This qualitative study has explored the health information needs about CAM and cancer for women affected by cancer. The study found three overarching health information needs for this target group: To be empowered (category 1), Accessible and understandable information (category 2) and Communications with HCP (category 3).

To be empowered

The participants in this study expressed with gratitude that the health information lectures provided them with a sense of being heard and seen. Seeking information is regarded as a major part of self-management and patient empowerment but is usually dependent on the healthcare system facilitating such opportunities for empowerment (Scott Duncan et al, 2022). By providing health information about CAM, a topic that is controversial and lacks easily available quality-assured evidence-based information, patients and those affected by cancer are being presented with an opportunity for empowerment. This sense of empowerment stems not only from the provision of the information itself but also from the acknowledgment of their interest in CAM and their willingness to contribute to their own course of disease.

By normalising CAM and validating their eagerness to learn more about this topic fosters a sense of legitimacy and respect for their perspectives. This validation is critical where patients often feel their preferences for CAM are dismissed or overlooked (Adler & Fosket, 1999; Eng et al., 2003) even though they would prefer receiving information about CAM directly from HCP (Wode et al. 2019). Information about CAM that is available online often lack transparent and evidence-based research (Delgado-López & Corrales-García, 2018; Ernst & Schmidt, 2002; Ng, Verhoeff, & Steen, 2023). Receiving quality-assured, evidence-based health information directly from HCP not only addresses these issues but also enhances patients' health literacy. Improved health literacy equips patients with the skills to critically evaluate CAM-therapies, making informed decisions and might act as a tool for empowerment (Crondahl & Eklund Karlsson, 2016).

Accessible and understandable information

The result in this study highlights the importance of knowing and understanding the target group to develop information that is accessible and understandable for their needs. A systematic review from Germany showed that health information needs could vary depending on gender, knowledge, age, education level or disease duration (Pieper et al, 2015). It is therefore important to make rigorous target group analysis to create initiatives with tailored information, though this is usually what is lacking in information initiatives (Jarlbro, 2010). Using different information disseminations with a combination of diverse forms of information without medical jargons is what indicates a successful communication initiative according to previous research (Ilic et al, 2023; Jarlbro, 2010). This approach ensures that information is both accessible and understandable, particularly for patients with varying levels of health literacy. For CAM-using cancer patients, this is especially important given the vast amount of information available, which can often be overwhelming or unreliable. As this study emphasises, these patients express a strong eagerness to learn more about CAM, making it vital to provide them with quality-assured and evidence-based resources. By addressing these needs through tailored information, the healthcare system could better support patients in making informed decisions about CAM use (SOU 2019:15).

Communications with HCP

The inquiry from the Swedish government from 2017 suggested that enhanced knowledge of CAM for HCP could support patients when navigating in CAM-therapies. If HCP knows more about CAM or know where to find evidence-based information about CAM, it could promote a safe communication between patients and HCP regarding CAM-related questions. Such efforts could help prevent potential negative interactions and enable patients to make informed decisions about CAM-therapies that are consistent with their personal values and beliefs (SOU 2019:15). This is also what the participant in this study inquires. They seek an open dialogue with HCP that is rooted in respect and evidence-based knowledge, which they believe could be achieved through greater knowledge about CAM within the healthcare system.

HCP could act like a barrier or a facilitator for information. To be listened to, taken seriously and met with respect fosters a trusting relationship that elevates feelings of empowerment and inclusion, which facilitates information acquisition (2023).

In recent years, the term expert patient or e-patient has gained attention, portraying a shifting power dynamic between HCP and patients. An expert patient is characterised by their great knowledge about their own course of disease and want to create innovative health promoting solutions to increase wellbeing together with HCP (Anampa-Guzmán et al, 2022). This growing patient expertise challenges the traditional authoritarian dynamic between HCP and their patients. Patients seek a collaborative approach where they get to take a bigger part of the decision-making process. This shift in power dynamics could explain why patients wish an increased communication with HCP that is based on equal participation. When HCP are equipped with evidence-based knowledge about CAM, they can engage more effectively with informed patients, fostering a sense of partnership rather than hierarchy. Such dynamics not only empower patients but also encourage an open dialogue, enabling them to make informed decisions that align with their values and beliefs while at the same time ensuring a safe combination of CAM and conventional treatment.

Discussion of method

The qualitative research method through interviews was chosen to explore the personal experiences and subjective reflections of the participants, which aligns with the core objectives of qualitative design. Its strengths lay in the possibility to understand the intangible and very personal connection the participants have with the research subject, whilst one of its weaknesses lies in the rigors planning that is needed to recruit and facilitate interviews (Danielson, 2017). For this study the time-consuming task of recruiting participants were a big hurdle, especially due to the limited timeframe of the study. Originally, the participants were planned to all be recruited from one and the same health information lecture but due to the lack of participant engagement, a total of three health information lectures were needed to recruit participants.

Between the lectures, the author together with a senior researcher from RCC and the supervisor from MIUN discussed on why an interest in participating in the study was lacking. This may possibly be because the research information did not sufficiently describe the importance of this study for those affected by cancer, to the vulnerable target group itself, or due to the observation that the number of participants that participated in the health information lectures were lower than expected on beforehand. To manage this, both the verbal and the written introduction of the study was shortened and made more concise whilst also adding another two lectures to recruit from. The study was limited to applying qualitative research design since the study was approved by the Swedish Ethical Review Authority with interviews as the data collection of choice. In hindsight, it might have been easier to recruit participants using a method with lower barriers of entry, as with a survey, but that would have had too much of an implication on the research aim. The author did manage to recruit a fifth and sixth participant for this study. However, the fifth participant withdrew from the study due to an unexpected connection to the author that was discovered during the interview, whilst the sixth participant was not available for an interview within the tight planning schedule of the study.

The challenges in the recruitment process resulted in a study of limited scale. To ensure credibility (Mårtensson & Fridlund, 2027), the author has had ongoing discussions with senior researchers as well as peer-reviewing from fellow students during the research process. The categories and sub-categories have also been debated to secure alignment in the result. Worth noting is the general characteristics of the participants. All of them were, in some shape or form, active in non-profit organisations or similar associations. They had a will to contribute to other women affected by cancer and had an interest in CAM in general, which presumably influenced their answers. If the timeframe of the study had allowed triangulation and a more diverse participant group, the results might have been different. To enhance dependability (Mårtensson & Fridlund, 2027), the author has highlighted reflexivity and pre-understanding that could have influenced the process of the study together with a thorough explanation of the data collection and data analysis.

The author wrote interview memos and mental notes during the data analysis, though this could have been more structured and in-depth. If the timeframe had allowed, additional peer-reviewing of transcriptions and the data analysis had also been beneficial for confirmability as well as doing test interviews (Mårtensson & Fridlund, 2027). Due to the limited scale of the scope and the unique context of the study, transferability is restricted to similar contexts and environments. To facilitate transferability further, it would have been beneficial to include supplementary questions regarding the sociodemographic of the target group and to provide further clarification of RCC as a context.

Furthermore, a few words regarding AI and data security management are needed. When the author joined this bachelor program, generative AI services and large language models were not prevalent topics, but it has recently started to become integrated into many aspects of the scientific world. However, research on the use of these tools in the research processes as well as data protection and ethical data management remain limited. For instance, the author tried to determine whether the "Dictate" function in Microsoft Word provided by MIUN used AI, but this information was not readily available. It is also unclear if and where the associated audio files are physically stored in Microsoft's back-end storage solution, where the cloud storage is located, which encryption technology is used and if third country access is possible. This could potentially be problematic in relation to laws on confidentiality and the General Data Protection Regulation [GDPR] and the need to securely store and process Personally Identifiable Information [PII] such as voice recordings of patients as Microsoft is a non-EU/EEA owned entity. While these issues and others related to AI deserve further exploration, they fall outside the scope of this study. The author hopes that by raising such questions, the increasing integration of ethical data management and AI into the research process will proceed in an ethical manner that is needed for safe, legal and secure data storage protection and data protection.

Conclusion

It is essential to understand health information needs of women affected by cancer to provide tailored messages that could meet their demand of information about CAM and cancer. If the information is presented in an accessible and understandable way for this group, it may empower them to make informed decisions about ways to support their health which could increase quality of life. This could also help foster a safe communication about CAM with HCP that is rooted in evidence and mutual respect.

Implications for further research

To broaden the knowledge of health information needs for CAM and cancer, further research should involve diverging population groups including varying demographic, gender, knowledge, socioeconomic, cultural and diagnostic backgrounds. Such studies could determine whether health information needs differ across groups, ensuring that the findings become more generalisable and inclusive. Furthermore, to deepen the understanding of health information needs for CAM in general, research could also extent further then the field of cancer addressing other public health issues such as heart disease, mental health or obesity. The findings in this study indicate that health information, if tailored to the specific target group and created with knowledge about the topic area, could lead to empowerment and greater health literacy. This advancement could enhance broader research on health information and communication strategies, contributing to stronger public health outcomes, particularly in this digital area.

Implication for public health policies

Access to objective evidence-based health information about CAM could empower women affected by cancer to make informed decisions and increase health literacy, fostering a supportive healthcare environment that respects patient autonomy, ultimately contributing to better wellbeing. To achieve this, coordinated efforts and collaborations between authorities, government agencies and medical schools are needed. Firstly, HCP needs access to evidence-based knowledge about CAM during their medical training to facilitate an open and trusting dialogue about CAM with

patients. Secondly, evidence-based CAM-therapies could be integrated in the healthcare system to meet patient demand and reduce stigmatisation. Thirdly, the public needs further access to quality assured health information about CAM that could support their decision-making process (SOU 2019:15). A clear mandate from the government administration is required to determine which authorities or government agencies should take ownership of these health communication initiatives. As of now, RCC had taken on the responsibility of providing health information about CAM to cancer patients though their work is limited and needs more audience tailored communication. Increased fundings could help develop information initiatives and communication strategies that meet target group demands. This approach aligns with the overarching goals of A2030 as well as the Swedish public health policies that aim to reduce health disparities, support patient-centred care, and improve quality of life for all. The findings in this report highlights the importance of addressing health information needs to bridge the gap between conventional medicine and CAM in a safe and effective way. Such effort could increase societal trust as well as ease the burden on the healthcare system. An equitable society must consider diverse health beliefs. By researching and developing health information and health communication initiatives tailored to specific target group needs, this work aims to contribute to a more open, health promoting and accepting society.

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Appendix 1 – Interview guide in English, translated for this thesis

Interview guide for interviews with people affected by cancer who participated in one of RCC Stockholm Gotland's information initiatives about complementary and integrative medicine (CIM) in cancer.

Questions

1. Which information event about CIM did you attended?
2. What were your expectations for the event?
3. What was your main takeaway from the information lecture?
4. What knowledge of CIM did you have before the information lecture?
5. Did you gain any new knowledge from the information lecture?
6. Have you since then gotten use of the knowledge about CIM that you gained through the information lecture?
7. Was there something you were missing at the information lecture?
If yes, what did you miss?
8. Is there any knowledge about CIM that you feel you're lacking after the information lecture? If yes, which one?
9. In what way could the information lecture have been better??
10. Where should you go if you still have questions about CIM??
11. Has your use of CIM been affected by the information you received during the lecture? If yes: in what way? If no: please elaborate.
12. What do you think about the dialogue about CIM with healthcare professionals? Difficulties and opportunities?
13. Is there anything else in relation to this information lecture or anything else about CIM that you would like to address?

Appendix 2 – Interview guide in Swedish, original

Intervjuguide för intervjuer med cancerberörda som deltagit i någon av RCC Stockholm Gotlands informationssatsningar om komplementär och integrativ medicin (KIM) vid cancer.

Frågor

1. Vilket informationstillfälle om KIM har du deltagit i?
2. Vad var dina förväntningar inför tillfället?
3. Vad var din främsta behållning av informationstillfället?
4. Vilken kunskap om KIM hade du innan informationstillfället?
5. Fick du någon ny kunskap efter informationstillfället?
6. Har du fått användning av den kunskap om KIM som du fick genom informationstillfället sedan dess?
7. Var det något du saknade vid informationstillfället? Om ja, vad saknade du?
8. Är det någon kunskap om KIM du saknar efter informationstillfället? Om ja, vilken?
9. På vilket vis hade informationstillfället kunnat bli bättre?
10. Vart skulle du vända dig om du fortsatt har frågor om KIM?
11. Har din användning av KIM påverkats av informationen du fick vid informationstillfället? Om ja: på vilket sätt? Om nej: utveckla gärna.
12. Vad tänker du om dialogen om KIM med vården? Svårigheter och möjligheter?
13. Är det något annat i relation till den här informationsinsatsen eller något annat om KIM som du vill ta upp?

Appendix 3 – Information letter in English, translated for this thesis

Information for research subjects

We would like to ask you if you would participate in a research project. In this document you will receive information about the project and what it means to participate.

What kind of project is it and why do we want you to participate?

Studies show that at least one in four people with cancer uses complementary and integrative medicine (CIM) in Sweden – but only one in three talks to their healthcare provider about this, even though many patients express a desire for such a dialogue. One way to increase this dialogue is targeted information and training initiatives both for patients and relatives as well as for the professions in cancer care. As we currently do not know enough about how information initiatives for patients in this broad area should be designed, this project is now being carried out with the aim of exploring experiences of information efforts about CIM at the Regional Cancer Center Stockholm Gotland.

You are asked to be part of this study after having participated in an information session about CIM at Regional Cancer Center Stockholm Gotland.

The research principal for the project is the Karolinska Institutet. Research principal means the organization responsible for the project. The research is approved by the Ethics Review Authority, the diary number for the review at the Ethics Review Authority is 2024-04426-01.

How is the project conducted?

Participating in the project means that a researcher will contact you one day to two weeks after the information session to agree on a time and place for an interview. The interview takes between 30-60 minutes. The interview is based on a few questions, and you are given space to bring up things that

you experienced as good, less good and downright bad with the information session. There will therefore be free space to express your experiences of the information session beyond the interviewer's questions. The interview is recorded so that the researchers can compile the experiences of several interviewees.

Possible consequences and risks of participating in the project

The risks of participating in the study are very small. Apart from being present at the interview, nothing is required of you as a research participant. The questions asked during the interview encourage you to bring up both positive and negative experiences of the training. It is fine to skip questions if you find them difficult or unpleasant to answer.

What happens to your data?

The project will collect and register information about you.

Your personal data as well as the recorded and printed interview will be processed so that unauthorized persons cannot access them. The printed interview will be coded immediately after printing. Any personal information that could lead to identification will be removed so that your statements will not be able to be linked to you as a person. When publishing, code names will be used. Only the project manager has access to the code key, which contains the information about which people have been given which code names. The code key and your personal data are deleted 10 years after the start of the project, i.e. Sep 2034.

Karolinska Institutet is responsible for your personal data. According to the EU's data protection regulation, you have the right to access the information about you that is handled in the project free of charge, and if necessary to have any errors corrected. You can also request that information about you be deleted and that the processing of your personal data be restricted. However, the right to erasure and to limit the processing of personal data does not apply when the data is necessary for the current research. If you want to take part in the data, you should contact the person responsible for the project, see below. Data Protection Officer Mats

Gustavsson can be reached at dataskyddsombud@ki.se. If you are dissatisfied with the way your personal data is processed, you have the right to submit a complaint to the Swedish Data Protection Authority, which is the supervisory authority.

How do you get information about the results of the project?

The results of the study will be published in scientific journals that are open to the public, with a so-called peer-review procedure. You will not be notified personally upon publication but can contact the person responsible for the project (see below).

Insurance and compensation

No insurance cover or compensation is paid when participating in the project.

Participation is voluntary

Your participation is voluntary, and you can choose to cancel your participation at any time. If you choose not to participate or wish to cancel your participation, you do not have to state why, and it will not affect your future care, treatment or the opportunity to participate in future information or educational initiatives through the Regional Cancer Center Stockholm Gotland.

If you wish to cancel your participation, please contact the person responsible for the project (see below).

Responsible for the project

Responsible for the project is Johanna Hök Nordberg, Karolinska Institutet, Institutionen NVS, 23 300, 141 83 Huddinge Johanna.hok@ki.se, Tel: +4670-79 72 954.

Appendix 4 – Information letter in Swedish, original

Information till forskningspersoner (cancerberörda)

Vi vill fråga dig om du vill delta i ett forskningsprojekt. I det här dokumentet får du information om projektet och vad det innehåller att delta.

Vad är det för ett projekt och varför vill vi att du ska delta?

Studier visar att minst en av fyra personer med cancer använder komplementär och integrativ medicin (KIM) i Sverige - och att endast en av tre pratar med vården om detta. Detta trots att majoriteten av patienter uttrycker en önskan om just en sådan dialog. Ett sätt att öka denna dialog är riktade informations- och utbildningsinsatser både till patienter och närliggande samt till professionerna inom cancervården. Då vi idag inte vet tillräckligt om hur informationsinsatser till patienter i detta breda område bör utformas genomförs nu detta projekt med syfte att utforska erfarenheter av informationsinsatser om KIM vid Regionalt cancercentrum Stockholm Gotland.

Du tillfrågas att vara med i den här studien efter att ha deltagit vid något informationstillfälle om KIM vid Regionalt cancercentrum Stockholm Gotland.

Forskningshuvudman för projektet är Karolinska Institutet. Med forskningshuvudman menas den organisation som är ansvarig för projektet. Forskningen är godkänd av Etikprövningsmyndigheten, diarienummer för prövningen hos Etikprövningsmyndigheten är 2024-04426-01.

Hur går projektet till?

Att delta i projektet innehåller att en forskare tar kontakt med dig en dag till två veckor efter informationstillfället för att komma överens om tid och plats för en intervju. Intervjun tar mellan 30-60 min. Intervjuaren utgår från ett antal frågor och det ges utrymme att ta upp saker som du upplevde som

bra, mindre bra och direkt dåliga med informationstillfället. Det kommer också finnas fritt utrymme att uttrycka dina erfarenheter av informationstillfället bortom intervjuarens frågor. Intervjun spelas in för att forskarna senare ska kunna sammanställa erfarenheter hos flera intervupersoner.

Möjliga följer och risker med att delta i projektet

Riskerna för deltagande i studien är mycket små. Utöver närvaro vid intervjutillfället krävs inget av dig som forskningsdeltagare. Frågorna som ställs under intervjun uppmuntrar till att ta upp både positiva och negativa erfarenheter av utbildningen. Det går bra att hoppa över frågor om de upplevs svåra eller obehagliga att besvara.

Vad händer med dina uppgifter?

Projektet kommer att samla in och registrera information om dig.

Dina personuppgifter samt den inspelade och utskrivna intervjun kommer att behandlas så att obehöriga inte kan ta del av dessa. Den utskrivna intervjun kommer att kodas direkt efter utskrift. Eventuell personlig information som skulle kunna leda till identifiering kommer att tas bort så att dina utsagor inte kommer att kunna kopplas till dig som person. Vid publicering kommer kodnamn användas. Endast projektansvarig har tillgång till kodnyckeln som innehåller informationen om vilka personer som har fått vilka kodnamn. Kodnyckeln och dina personuppgifter raderas 10 år efter projektstart, dvs Sep 2034.

Ansvarig för dina personuppgifter är Karolinska Institutet. Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i projektet, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna ska du kontakta ansvarig för projektet, se nedan. Dataskyddsombud Mats Gustavsson nås på dataskyddsombud@ki.se. Om du är missnöjd med hur

dina personuppgifter behandlas har du rätt att lämna in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får du information om resultatet av projektet?

Resultaten från studien kommer att publiceras i vetenskapliga tidskrifter som är öppna för allmänheten, med så kallat peer-review förfarande. Du kommer inte att underrättas personligen vid publikation men kan höra av dig till ansvarig för projektet (se nedan).

Försäkring och ersättning

Inget försäkringsskydd eller ersättning utgår till följd av deltagande i projektet.

Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, och det kommer inte heller att påverka din framtida vård, behandling eller möjlighet att delta i framtida informations- eller utbildningsinsatser genom Regionalt Cancercentrum Stockholm Gotland.

Om du vill avbryta ditt deltagande ska du kontakta den ansvariga för projektet (se nedan).

Ansvarig för projektet

Ansvarig för projektet är Johanna Hök Nordberg, Karolinska Institutet, Institutionen NVS, 23 300, 141 83 Huddinge Johanna.hok@ki.se, Tel: 070-79 72 954.

Diva

At Mid Sweden University, it is possible to publish the thesis in full text in DiVA (see appendix for publishing conditions). The publication is open access, which means that the work will be freely available to read and download online. This increases the dissemination and visibility of the degree project.

Open access is becoming the norm for disseminating scientific information online. Mid Sweden University recommends both researchers and students to publish their work open access.

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- Yes, I/we agree to the terms of publication.
- No, I/we do not accept that my independent work is published in the public interface in DiVA (only archiving in DiVA).

Stockholm, 2025-01-23

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Location and date

Folkhälsovetenskapliga programmet, FH038G Folkhälsovetenskap GR (C)

.....

Programme/Course

Sandra Gärtner

.....

Name (all authors names)

1991

.....

Year of birth (all authors year of birth)

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