A Qualitative Focus Group Study for the Exploration of Knowledge and Attitudes of Informal Caregivers Toward Breast Cancer: Perceptions of Informal Caregivers and Healthcare Professionals in Three European Countries

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Abstract
Breast cancer (BC) early screening and detection is a main component for the outcome of the treatment and overall survival. Informal caregivers (ICGs) are less likely to initiate early BC screening methods and utilize health services. The purpose of this study was to explore ICGs’ knowledge and perceptions, including educational and training opportunities or barriers, in promoting early detection practices for BC, as well as healthcare professionals’ (HCP) respective perceptions concerning ICGs in order to identify the need of selected health literacy interventions. A qualitative focus group study was implemented in 3 European countries, using a purposive sampling technique. In total, 26 ICGs and 18 HCPs were involved. The themes that emerged from the focus groups interviews included knowledge, perceptions, attitudes, and beliefs concerning BC; motivational factors and barriers that influence early screening practices and personal involvement. Motivators and barriers concerning BC screening adherence were linked to knowledge, beliefs and perceptions. Health promotion strategies and user-friendly tools should be developed, targeting on the implementation of BC early detection practices among informal caregivers.

Keywords
breast cancer, breast cancer screening, caregiving role, informal caregivers

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Highlights

What do we already know about this topic?
Women informal caregivers face additional challenges in engaging in health promotion activities such as breast cancer screening.

How does your research contribute to the field?
The development of a mobile phone-based health intervention can enhance preventive healthcare behavior among informal cares’ population with tailored individual messages, as well as presenting pedagogical material and relevant information.

What are your research’s implications toward theory, practice, or policy?
The impact of affecting change and reinforce positive behaviors and encouragement informal carers, to use monthly breast self-examination and to use regularly preventive services in the context of early detection of breast cancer.

Introduction
Breast cancer (BC) can be an early detectable disease partly due to the effect of specific health promotion activities that focus on secondary prevention. This can be achieved through health education and health awareness that support behavioral changes, such as regular breast self-examination (BSE), clinical breast examination, and mammography, leading to early detection and treatment. Breast self-examination is an important screening method that can be performed by a woman on herself at no cost whilst its contribution and effectiveness in the early detection of BC has been demonstrated in the relevant literature.1-4

The outcome of BC treatment largely depends on the timing of its detection. Although national health systems throughout Europe follow the European Union’s (EU) recommendations for the provision of mammography screening to detect BC in an early stage,5 women’s adherence to screening programs is relatively poor.6,7 The average attendance in the EU was below the standard acceptable level of 70%.8 This can be partly attributed to the fact that the general public’s knowledge on the effect of screening programs is scarce. Relevant research suggests that only 1.5% of the citizens of Europe know the actual benefits of participating in BC screening9 whilst demonstrating also the many disparities across European countries.1

Informal caregivers (ICGs) are generally defined as persons who provide unpaid assistance or supervision with personal or instrumental activities of daily living toward a person (ie, relative or friend) who is unable to perform these activities due to cognitive, physical, or psychological impairments.10 Caregiving of a person with a chronic disease can also be a contributing factor, leading to the lack of BC information, health behaviors, and screening adherence. According to data, caregivers are less likely than non-caregivers to practice health-promoting behaviors.11-13 It is possible that the caregiving role may reduce the amount of time available to engage in preventive health services. Studies showed that the majority of caregivers of people with major caregiving needs were unable to leave the care recipient alone and had to organize their time according to the daily activities of the recipients.12-14 Other studies have shown a significant association between caregiving level and inadequate exercise and health promotion practices.15-17

Evidence suggests that self-management and self-efficacy improves people’s motivation and confidence in their own ability, knowledge, experience, and satisfaction.18 Interventions aiming on ICGs knowledge were shown to empower their self-efficacy.19,20 Supporting self-management also strengthens people’s engagement in more healthy behaviors and encourages general behavioral changes.21 Studies on the topic have identified several facilitators that have been found to promote increased mammography use in women. The noted factors include perceived benefits of mammography, self-efficacy, and susceptibility to BC.22,23

Limited health literacy is associated with the limited use of preventive services across cultures and population24-26 and women with inadequate self-reported health literacy were less likely to have had a mammography in the last 2 years.27 Additionally, inadequate health literacy has been linked to greater risk for cancer and presenting to cancer care systems at more advanced stages of the disease.21

Data from various research areas conclude that health literacy aiming interventions can shift perceptions of women toward BC screening.28-31 Technology derived interventions are feasible and provide a cost-effective method of early BC screening.32,33

Caregiving has been identified as a significant factor that can lead to poor utilization of healthcare services in the early stages of BC.34 Informal caregivers may be less likely to meet their own health needs, face higher allostatic load levels, and have higher levels of mortality and morbidity as they age.35 Studies have emphasized ICGs impaired health behaviors, such as neglecting their own healthcare appointments and non-seeking cancer screening tests compared to non-caregivers.36-38 As nearly two-thirds of ICGs aged over 50 are women,39 the burden of caregiving raises concerns regarding women’s health including BC screening and overall preventive behaviors.

The purpose of this study was to explore ICGs knowledge and perceptions, including educational and training opportunities or barriers, in promoting early detection practices for BC, as well as healthcare professionals (HCPs) respective perceptions concerning ICGs in order to identify the need of selected health literacy interventions.
Methods

Study Design

A qualitative focus group study was implemented. The decision to utilize this method for retrieving the research data was informed by the topic under investigation as well as the type of information needed by the respondents. The researchers believe that through this method allows an open discussion with the participants and between the participants themselves the desired information could be attained in a natural environment. Participants were encouraged to freely express their feelings, ideas, agreements or disagreements in a non-threatening environment. Furthermore, discussions stimulated memories and facilitated the exchange of ideas and opinions, leading to a more in-depth study of the research topic.

Setting

The interviews took place in 3 European countries, namely, Cyprus (CY), Italy (IT), and Portugal (POR), using the interviewer’s country local language. Each country recruited an experienced person as the moderator of the focus groups. The moderators were healthcare professionals with expertise in health promotion issues and relevant experience in focus groups moderation.

Sampling Strategy

The target population of the study consisted of female primary ICGs, over 55 years old of a person diagnosed with a chronic disease (cancer, dementia, and myopathy) and HCPs, experts on BC with working experience ≥2 years. Both groups were recruited from the aforementioned 3 European countries according to the above-predetermined criteria.

Informal caregivers were informed about the study by their allocated community nursing services of each country involved. Each community service would then bring the caregivers that were interested in contact with the research team. Healthcare professionals were informed from non-government organizations (NGOs). A brief meeting of NGOs with the researchers was preceded, aiming to inform them on the scope of the research.

Purposive sampling technique was used in order to achieve the desired homogeneity and heterogeneity of the groups. Homogeneity was achieved by selecting participants that assumed the role of ICGs of a chronic patient. Heterogeneity was achieved in terms of their care experiences, age, and type of provided care (ie, people with dementia, myopathy, and cancer) so that it is possible to express different or even contradictory views. A purposive sample of experts was selected, following analysis of the data from the focus groups with the ICGs.

The sample size and the consequent extension of focus groups were determined based on the phenomenon of thematic saturation of the information that emerged from the simultaneous collection and analysis of the data.

Ethical Issues

The National Bioethics Committee according to National Law approved the study’s protocol for ethical approval by each participated country (CY EEBK EP 2019.01.215; IT n° 42499 February 28, 2020). Participants signed an informed consent form following the provision of detailed information on the study. The participants were informed on the voluntary nature of this study and that they retained the right to withdraw at any time from the study. All data were kept safely with access limited only to the members of the research team and only for the purposes of the present study and will be destroyed after the completion of the study and according to National Law. Confidentiality was maintained throughout the research process.

Data Collection

The moderator of each country used a semi-structured interview guide during the interview for both ICGs and HCPs groups, in order to provide a degree of content structure and comparability to the focus group discussions. The guide was developed by the researchers in Cyprus and included 19 questions for ICGs (Table 1) and 4 questions for HCPs (Table 2).

Focus groups followed an identical research process for retrieving the data and were digitally recorded for later verbatim transcription. The process was simultaneously held from January to May 2020, in all countries involved.

Data Analysis

Data analysis was implemented with the principles of descriptive thematic analysis. Thematic analysis as an independent qualitative descriptive approach is mainly described as “a method for identifying, analyzing and reporting patterns (themes) within data”. More specifically, within each transcript, relevant themes (ie, words, phrases) were highlighted and coded under headings (ie, categories). When significant differences were recorded, those were moderated to different groups accordingly.

In order to enhance trustworthiness, all interviews were audio taped. Data were analyzed by examining the audio tape transcripts and the themes were identified and grouped by 2 pairs of researchers independently. This was followed by a consensus meeting where any differences in the produced themes and categories were discussed and moderated. The data analysis was performed in Cyprus for all research sites.
Results

Five focus groups with 26 ICGs and 3 focus groups with 18 HCPs were formed using a purposive sampling. Participants’ characteristics for both groups are demonstrated on Table 3. Significant differences were found in the average amount of hours that ICGs devoted to caring, with the longest time reported in Portugal (mean 49.60; SD 65.93), followed by Cyprus (mean 31.27; SD 31.40) and Italy (mean 21.00; SD 15.90).

Informal Caregivers Focus Groups

Five themes emerged from the interviews of ICGs: Knowledge and perceptions on BC, Attitudes and Beliefs on BC, Motivational factors that influence early screening practices, Barriers influencing early screening practices, and Personal involvement. Each theme was further analyzed to subcategories (Figure 1).

Knowledge and perceptions on BC. All participants reported to have knowledge of BC prevention practices including BSE and CE. They recognized the value of screening tests such as mammography. Interestingly, however, neither performed BSE. Reasons for not performing BSE included lack of knowledge concerning the procedure and discomfort (“feeling uncomfortable as a practice or feeling fear” (P4 IT)). Most of the participants stated that they would either not remember to perform BSE or execute the right procedure, indicating that they did not adopt a systematic behavior in relation to performing BSE. These factors have contributed to gradually abandon the practice itself. During the palpation attempt, some participants also noted that they were not aware of how to interpret an abnormal finding or what they had to feel. Most of them felt safe with mammography and ultrasound screening tests (provided by national programs), considering BSE less important, with participants having the tendency to underestimate its value, “Yes, for sure! Very important! And, if you find it, I think it will be easier to manage cancer if you find it at the earlier stage” (P7 CY). “The earlier the diagnosis, the better. I think people today are also more aware of this and in fact WHO has been warning. There is no one who is not afraid of this disease or who has not heard of it” (P4 POR).

Greek-Cypriots and Portuguese women kept a positive attitude and an optimistic way of thinking about the diagnosis of BC. Participants reported that screening tests would help them with early detection and early intervention of BC, “Yes, screening could help” (P1, 2,3,4,5 IT).

Attitudes and beliefs on breast cancer. Most of the participants were frightened about the issue of BC, but this fear reflected
differently on their early detection modalities. For example, some of the participants’ comments showed an attitude of avoidance out of fear or driven by fear. “It scares me because I knew people who got cancer. For this reason, whenever there’s a chance to go to screening appointments, I take the opportunity and I go” (P2 IT). Others did not perceive themselves as being at risk, or had an attitude toward simply carrying out the strictly necessary practices, “I’ve never been worried about it or even wanted to think about it (...) If I have nothing, what am I thinking about? I already have so much to think about, not to think about one more (...) I don’t prevent myself from anything” (P3 POR). In both cases, the participants’ attitudes were not based on scientific information or on healthcare specialists’ recommendations.

Formal caregivers attitudes toward BSE were linked to knowledge, beliefs, and perceptions. Some participants avoided this practice, devaluing its benefits, “Honestly, I do not perform BSE often, I feel safe because I am doing my mammography and ultrasound tests. Keeps me safe” (P10 CY), “I can’t do it... but I think it is partly because I feel safe

Table 3. Characteristics of ICGs and HCPs.

|                      | CY n (SD) | IT n (SD) | POR n (SD) |
|----------------------|-----------|-----------|------------|
| **Informal caregivers** | 9         | 5         | 12         |
| Mean age (years)     | 52.33 (3.90) | 58.60 (8.98) | 61.73 (5.02) |
| Providing care to loved ones (months) | 11.19 (8.99) | 11.19 (8.99) | 11.19 (8.99) |
| Number of hours devoted to caregiving | 31.27 (31.40) | 21.00 (15.90) | 49.60 (65.93) |
| **Healthcare professionals** | 5         | 4         | 6          |
| Highest Level of Education (all countries) |                      |                     |            |
| Bachelor’s degree   | 5         |          |            |
| Master’s degree     | 6         |          |            |
| PhD                  | 4         |          |            |
| Occupation (all countries) |                  |                     |            |
| Social assistance   | 2         |          |            |
| Psychologist        | 8         |          |            |
| Biologist/nutrician | 1         |          |            |
| Oncologist doctor   | 1         |          |            |
| Associate professor in public health | 1       |          |            |
| Physiotherapist     | 1         |          |            |
| Years of total experience [mean (SD)] | 14.80 (8082) |             |            |
| Years in current position [mean (SD)] | 8.67 (5219) |             |            |

Note. ICG: informal caregivers; HCPs: healthcare professionals.

Figure 1. Themes and sub-themes identified by the analysis of informal caregivers focus group.
from keeping up with my ultrasound and mammography tests... By this way I can detect cancer early” (P5 CY).

Fears were expressed, resulting from the lack of knowledge concerning examination procedure. For example, some participants reported that they were afraid of the radiation of the specific test (ie, mammography). “...is this safe to do every year mammography... I am afraid of radiation!” (P4 CY). “Radiation will damage other organs, causing osteoporosis, etc.” (P4 POR). On the other hand, participants who had a family history of BC reported that they would undergo mammography on a systematic basis.

Although Cypriot and Italians believed that there is a possibility to get diagnosed with BC, they were not particularly concerned by that possibility. They did not consider themselves in risk of being diagnosed with BC, except in cases where a strong family history existed. “Yes, I believe that there is a risk because I already got sick from thyroid cancer and my mother had cancer in uterus... I am afraid from other types of cancer” (P6 CY).

Participants believed that genetics is the main risk factor for BC. “This is going to be genetic because many of us have it. My mother died at the age of 54 with BC” (P4 POR). Most of them agreed that maintaining a healthy lifestyle would help prevent the disease. “Yes, I try to eat healthy and doing physical exercise, but it is difficult for me to do it regularly” (P5 IT). Others believed that other factors including smoking, nutrition, stress/anxiety, and environmental pollution have an impact on the occurrence of the illness, “I think it has to do with both food and tobacco” (P2 POR).

Consequently, the beliefs developed were consistent with the style of prevention adopted, everyone was aware that screening can be useful for early detection of BC, but a gap existed between the perception of danger and the implementation of screening practices.

Motivational factors. Several factors were found to encourage participants in utilizing BSE including past illness experience, “(Yes)... after my mom’s breast cancer I do mammography systematically, furthermore I have a mastopathy as well that I have to watch it” (P3 CY), the responsibility of the person they care for “Positively, I need to take care of myself in order to take care of others too” (P4 IT), a healthcare professional “A Gynecologist motivated me to do my test, after my aunt died from breast cancer” (P10 CY) a friend or a family member “It scares me because I knew people who got cancer. For this reason, whenever there’s a chance to go to screening appointments, I take the opportunity and I go” (P2 IT) and awareness campaigns from non-profit organizations “Advertisements, Europa Donna” (P8 CY).

Barriers influencing early screening practices. The barriers that emerged included lack of time to think about and perform BSE practices, “Sometimes I have the feeling that I do not have enough time to have a shower and therefore performing BSE is somewhat a luxury!” (P2 CY). Difficulties approaching healthcare settings due to caregiving role also emerged, “I’m scared to receive bad news about illness. I’m a caregiver and I can’t get sick so, even if it’s a stupid reason, I prefer not to know” (P1 IT). Other barriers that emerged were lack of knowledge and skills “In my case, it’s the lack of knowledge” (P7 POR), “The only think I don’t do on my own is BSE, I don’t know how to do it....” (P5 CY), fear of discovering anomalies/of getting sick “...maybe it scares me” (P10 CY) fear of discomfort and pain during the screening tests “BSE is uncomfortable, no doubt. Mammography is a bit painful procedure” (P1 POR) and forgetting/failing to practice an early screening routine.

Personal involvement. All participants agreed that their caregiving role changed their life on many different levels (psychological, emotional and social and physical level). Some of the participants described feelings of guilt, anger, nervousness, loneliness, depression, anxiety, tiredness and exhaustion and fear of losing the person they cared for, “When you close your door, you are alone! Of course, change my life 180’. I see life differently now... I prefer to be at home alone. I rarely go out” (P1 CY).

This experience allowed ICGs to find some positive aspects for their life, like changing priorities and feeling satisfaction for offering care to the other person. Some participants mentioned that they held responsibility toward the person they cared for and their family, to undergo regular screening tests. Others declared that due to their role, had given up their personal care in order to dedicate themselves to the recipients, leading them to miss or postpone appointments, “.... I left appointments behind. For example, now I wanted to visit an ophthalmologist but I left it behind” (P2 CY).

Healthcare Professionals Focus Groups

From the HCPs interviews, the main themes that emerged included motivational factors and barriers toward BC early screening practices for ICGs.

Motivational factors. According to HCPs, the sense of responsibility toward oneself comprised a considerable factor, “Informal caregivers are usually looking for psychological support for own self, instead for the person who is ill and we really encourage this, because cancer is a stressful experience for the whole family and not just for the person who gets diagnosed with breast cancer” (P2 CY).

Genetics determination of BC, also stood as an important motivator for seeking early BC screening, “Informal caregivers have a potentially increased chance of developing breast cancer due to family history... they know this... it creates a feeling of responsibility of their health” (P3 CY).

Barriers. A substantial barrier toward early screening practices from ICGs, according to HCPs, was the lack of time, “I
agree it’s a matter of time...they also have the burden of caring for a sick person, so it is an additional burden that they have to take care of their own people, as a result they put themselves in a second place. If they have a mammogram, they will do for their mothers they will not do for themselves” (P1 CY); “Yes. In the final stages of the illness [of the patient] the exams are more often postponed or skipped by the informal caregivers” (P2 IT); “women do not go because they are ICG and call to say they cannot do the screening that day, at that time because they are taking care of a person (...) even more with cancer patients with comorbidities (eg, dementia), in these cases ICG can’t even leave them alone” (P3 POR).

All HCPs identified illness and suffering, as the main fears. Participants mentioned that if an ICG would get ill, they would no longer be able to take care of their loved one. “There is a sort of sense of guilt because at that moment you are taking care of yourself rather than of your loved one” (P1 IT).

Fear of suffering was also related to the treatment itself. Therefore, according to the participants, a second fear was linked to oncology, regardless of one’s role as a caregiver, as it awakened the fear of dying. “The fear of suffering, already when they simply go for a mammogram. They are afraid of the cure because it itself create suffering. This makes everything more frightening” (P3 IT). “The woman is also very afraid to find something. And afraid to find it, she prefers not to do palpation” (P5 POR).

Moreover, HCPs believed that many ICGs deduced themselves by believing that as long as they did not perform a medical examination, they would not get sick; they preferred not knowing the outcome of the examination, in order to consider themselves healthy, “The fear of getting sick. They think: if I go to the visit, I can discover that I am sick, as long as I don’t go, I remain healthy” (P1 IT), “...many times, the avoidance of dealing with or approaching a difficult problem may be a defence mechanism in an additional traumatic event. They experience a traumatic event...the diagnosis of their own person so it may be a subconscious defence mechanism to avoid” (P2 CY). “They devalue, they think that it only happens to others, the truth is this, is that this is still lived a lot, it only happens to others” (P6 POR).

Furthermore, HCPs mentioned that lack of knowledge and time on behalf of ICGs were also barriers linked to non-practicing BSE, “Lack of knowledge, because they don’t know how to do it. And because they are not aware of the importance of. I think it’s a lot of ignorance, because they have no perception of how it works” (P6 POR). “Is the wrong way. I mean they do not know how to do BSE in the right way. I mean they do not know exactly how to do it” (P5 CY).

Difficulties in approaching healthcare services were also a negative determinant for the utilization of early screening, “Provinces have lesser adherence [to the prevention exams] than cities. I think sometimes it’s a cultural and mentality issue. Some women think: if I hadn’t done the exam, I wouldn’t have gotten sick.” (P2 IT). “It’s true. In the countryside and in the mountains, going to the doctor is something exceptional, which is done when you feel terrible.” (P3 IT).

Discussion

This qualitative study had a two-fold aim: First, to explore ICGs knowledge on BC and their perceptions on educational and training opportunities and barriers in promoting prevention and second, to identify education needings topics concerning BC and screening, from HCPs perspectives.

Our findings showed that ICGs were fully informed about BC in general and comprehended the benefits of screening. Women were more likely to be consistent with screening methods when they had personal or familiar experience of BC and when they received specific advice and encouragement by their physicians. Similar findings were supported by Hassan et al.44 This behavior can be explained by the fact that women take actions to prevent BC because they perceive themselves to be susceptible to the condition. Based on the Health Believe Model, engagement in mammography and ultrasound can be predicted by women’s perceptions about BC derived from their knowledge about the disease.45-47

In our study, women with an increased risk for developing, or with a previous history of BC did not incorporate BSE into their daily routine. This is possibly due to the fact that ICGs view this technique as time-consuming, while they did not feel well trained to successfully undertake this procedure with confidence. This appears to be a consistent finding in the relevant literature, with preceding studies, revealing that most women were unaware of how to perform BSE, stressing the existence of a gap concerning education and promotion of BSE among women.23,48-50

There appears to be a consensus among ICGs and HCPs that participated in this study. For example, both groups argued that barriers for ICGs on performing BSE included the lack of time due to their caregiving role and of confidence and technique familiarity. The burden of caregiving has been found to be a negative predictor for BC screening in other studies.38,51

Participants often devalued the BSE procedure because they perceived that the combination of mammography and ultrasound procedures was much more reliable and trustworthy compared to BSE. The devalue of BSE was also found in other studies.52,53 Encouragement for BSE training is needed from HCPs in order to empower women to adopt a systematic behavior concerning BSE combined with mammography and ultrasound procedures.

Healthcare professionals focus groups opinions and knowledge, coherently described a unique reality which was consistent with the narration from the ICGs focus groups. From the HCPs perspectives, ICGs tended to adopt 2 macro categories of behaviors related to the prevention of BC. In both categories, the experience of caring for a loved one
diagnosed with BC, was a powerful influential event in the ICGs life.

The first category was characterized by ICGs that due to their “commitment to care,” “lack of time,” and “fear of cancer” did not adhere to early screening practices. These findings were consistent with those of other studies that demonstrated that the majority of ICGs of people with major caregiving needs were unable to leave the care recipient alone and had to organize their time according to the daily activities of the recipients.11-13,49

The second category, according to HCPs, was characterized by ICGs who because of their care experience were meticulous in following early screening practices declaring “responsibility towards the person they care for” and “own family” and “the high risk to get cancer.” Adherence of ICGs toward BC screening, compared to controls, was also described in a study by Rha et al.16 These motivational factors reported from HCPs were in accordance with the ICGs expressions.

The barriers that emerged from this study that influenced the behavior of ICGs, concerning early screening, might have been the result of the wrong perception women have on BC diagnosis. Therefore, providing programs that promote health literacy, focused on BC and the significance of screening methods, including BSE, could reduce concerns and motivate them to practice BSE in a systematic basis.28-30 The promotion of alternative, technology enhanced tools could facilitate the empowerment of women in such basis.33,54

Limitations
The involvement of different countries is considered a strong benefit for the study as it provides a wider perspective to the topic at hand. On the other hand, the different languages and the involvement of different researchers during transcription should be treated with reluctance. This potential limitation was however mitigated by placing translation processes according to international recommendations. Furthermore, the centrally developed guide provided to all researchers helped to minimize methodological discrepancies. The results cannot be generalized to all women because the information was exclusively collected from women who were engaged as ICGs. Personal characteristics and demographic variables were not included in the study, limiting associated conclusions from the results of the study. Future research could include personal characteristics and demographic variables in order to capture the complexities as well as interactions among barriers and other determinants of health behaviors.

Conclusion
Motivating factors and barriers for BC screening adherence were linked to knowledge, beliefs, and perceptions. Health promotion strategies and user-friendly tools should be developed, targeting on the implementation of BC early detection practices among ICGs. The establishment of technology-enhanced tools, in order to increase the dissemination of information about BC and emphasize the importance of BSE and other screening methods, could lead to the early detection of BC.

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