International Journal of Innovative Research in Medical Sciences (IJIRMS)
ISSN (Online): 2455-8737, Vol. 01, Issue 07, Sept 2016
Available online at – www.ijirms.in

The Experience of the Family of the Woman with Breast Cancer: Metasynthesis

Anna Cláudia Yokoyama dos Anjos - citation: Anjos, ACY
Marcia Maria Fontão Zago - citation: Zago, MMF

Abstract:

Objective: To synthesize qualitative studies on the effects of the family's experience in caring for the woman with breast cancer.

Method: Systematic review-Metasynthesis. Primary studies, available online, article format, Portuguese and English were included; databases: PsycInfo, PubMed, CINAHL, EMBASE and BVS. Studies were evaluated using the consolidated criteria for reporting for qualitative research (COREQ-32).

Results: Final sample of 18 studies; four units of senses were built: chaos caused by the cancer; common sense and the stigma of cancer; emotions and reactions during the course of cancer; joining of forces: family's attitudes and strategies in the experience of caregiving. Central meaning of the experience: "maintaining the course of life by joining forces." Conclusion: In this chaotic trajectory experienced by the family, joining forces provided balance to maintain life. Further research aiming at expanding the understanding of the experience, contributing to evidence-based practice is suggested.

Descriptors: Breast Neoplasms; Family; Medical Anthropology; Oncology; Qualitative Research.

Introduction

Breast cancer affects women of all ages, ethnicities, socioeconomic status, and geographical regions; it is considered the highest incidence cancer among women. In Brazil, 57,960 new cases were estimated for 2016(1).

Due to the chronic nature of the disease, and the peculiarities of the process of the disease and its treatments, the involvement of the patient, the family, the support networks, and the qualified healthcare professionals is necessary. As for the caregiving, the family has been featured with an important collaborative role in coping with the disease and caring for the ill woman during the treatment (2).

The prolonged treatment, the effects of the adverse reactions, the impairment of the physical, social and psychological functions are immense for the life of the woman with breast cancer and her family. Thus, this woman needs care, requiring from the family adjustments, changes in the roles, and in the daily routine (3-5).

Family-provided home care was considered in the development of the National Health Policy, and it has been encouraged aiming at de-hospitalization, closeness and relationship among the family members, in addition to sharing activities in order to achieve better caregiving(6). However, it can be observed that the family feels unprepared for the job, incapable, vulnerable and insecure, leading to exhaustion, overload, and finally, frustration, despite all the loving and caregiving strategies (3-4,7).

The home care experience provided by the family to an ill family member is influenced by each individual, considering their own life experiences, the access to health services, the diagnosis and proposed treatment, and its effective fulfillment (5,8). The experience is organized by history, culture and situations experienced by people, expressed by means of the language. Life experiences are symbolic cultural expressions socially constructed, how people act in the world. This is how the concept of experience adds to the notion of illness, for being ill includes experiencing the symptoms, the suffering, the body process monitoring, and the explanations about the disease process according to the senses of the common sense reported by the ill, and by the family when coping with the disease (9). Hence, the home care experience is the opportunity for the family to learn and to care for an ill family member.

The qualitative methodology, its methods, and theoretical references enable the researchers to explore the relationships, the senses and meanings of the experiences, by means of sociocultural constructions (10).

Despite the development of the research focusing on the caregiving experience provided by the family to the cancer patient (4,7), a mismatch between the increase in the production and the application of the results in the healthcare practice can be observed. Thus, it is necessary to gather, synthesize, and facilitate the access to new knowledge to better caregiving planning, accounting for a systematic literature review.

The aim of this review was to synthesize qualitative studies on the effects of the family's experience in caring for the woman with breast cancer, and to understand its meaning.

Method

The systematic review enables the synthesis of primary studies, in which objectives, materials and methods are clearly shown; it is conducted according to clear and reproducible methodology for the identification of studies, which are critically evaluated, and subsequently synthetized; it requires planning, and the use of protocol for all the data recording (11).

It is noteworthy the lack of consensus on the best way to develop a systematic review of qualitative studies. Among the different methods, metasynthesis stands out for the dissemination, and interpretative contextualization of the knowledge. Its methodology includes an analytical process with conceptual understanding, and interpretation of the results of studies derived from ethnography, phenomenology, grounded theory, among others that characterize studies of such nature (12-14).

The seven steps of the metasynthesis approach were followed (12): identification of the area of interest; selection of studies; readings to identify the themes, metaphors and concepts; decision of the studies to be reported; reciprocal translation among the studies; synthesis of the reciprocal translation; report of the synthesis – metasynthesis. The review was led by the following guiding question: *What is the family's experience in caring for the woman with breast cancer?*

The bibliographic survey was carried out from March to June 2013, with no time-window limitation, aiming at retrieving the greatest number of publications via Online Search Systems, and Literature Analysis in the databases: (*US National Library of Medicine*) – PUBMED, (*Cumulative Index to Nursing and Allied Health Literature*) – CINAHL, American Psychological Association database (APA) – PsycINFO, in the Search Portal of the BVS - Biblioteca Virtual em Saúde (Virtual Health Library) and EMBASE. Relevant studies were found by crossing Health Sciences descriptors (DECs) and Medical Subject Headings terms (MeSH): *pesquisa qualitativa OR qualitative research; neoplasias da mama* OR breast neoplasms, família OR family, interrelated by the Boolean operators AND; OR. The descriptors of the PsycINFO database are specifics, but they corresponded to the DECs descriptors. The inclusion criteria for the sample composition were: a) publications of primary studies available online in article form with explicit reference to the use of the qualitative method; b) summary and full texts in Portuguese, English and/or Spanish; c) national and international publications related to experience; d) articles written by researchers in the field of Health and related to this field.

In view of the wide range of concepts and criteria of what constitutes the rigor in quality in qualitative research (15), we kept all the studies that fulfilled the inclusion criteria, although it was not possible to answer all of the instrument used for the assessment of the quality of the studies (Consolidated criteria for reporting qualitative studies – COREQ – 32), as described in a study that considered relevant to keep the published papers that allow to answer the review questions (11). COREQ-32 is a 32-item checklist, divided into 3 (three) areas: research team and reflexivity; study design; data analysis and results (15). The instrument COREQ-32 was translated into Portuguese, and validated by experts, before being used to assess the articles.

After the initial reading of the 812 titles and summaries, 57 studies were pre-selected for full reading, and application of the instrument COREQ. Repeated articles and the ones that did not meet the inclusion criteria were excluded. The final sample of this review amounted to 18 studies, identified by the letter E followed by a sequence number (E1, E2, E3...).

Characterization, assessment of objectives, and theoretical and methodological aspects of the studies followed. After several readings focusing on the results, we sought to identify the concepts and themes, for the reciprocal translation among the studies, by means of comparison among themes and concepts (12).

Considering the family's experience during the cancer process and treatment, which is built and supported in the different cultures, and in the people's common sense, we sought similarities, convergences and divergences among the studies. The results were grouped in units of senses; and subsequently analyzed and interpreted in the light of Medical Anthropology, which integrates the concepts of health, disease, and culture as a result of the relationship between the biological and the cultural as social construction, enabling the construction of the central meaning. In order to set the hermeneutic circle, we sought to relate the parts and the whole, where the whole and the parts are accounted for by means of dialectic interpenetration (16,17). Culture is a network of meanings that sustains the norms, values, and social practices. Meaning is built within this network, influenced by the context where occurs; providing parameters for producing ways of thinking, conducting actions, and real and temporal social interactions (18,16). Medical Anthropology verifies, from the sociocultural diversities, how people interpret the experience of the disease and its treatments (9).

This analysis was carried out by the first author of this study, and it was discussed and validated with the second author.

Results

The final sample comprised 18 studies, indexed on the following databases: one (1) article on EMBASE, four (4) on PUBMED, eleven (11) on CINAHL, two (2) on PsycINFO. There were many repeated studies (58) on the different databases, and they were accounted for only once. 794 studies were excluded from the initial search.

According to the characteristics identified, the researchers, in most cases, were professors linked to educational and/or assistance institutions. As for language, publications in English prevailed (17). The studies were carried out in different countries: United States,

Canada, United Kingdom, Australia, Brazil, Hawaii, Hong Kong and Korea; thirteen (13) were carried out in Teaching Hospitals and/or Universities. Table 1 shows the characterization of the studies included in this metasynthesis. The information contain: study sequence number, database where they were retrieved, titles of the articles, journals in which they were published, authors, country where the study was carried out, year of publication.

Table 1 – Identification of the studies of the review. Ribeirão Preto. SP, Brazil. 2014

	Database	Article Title	Journal	Authors	Country	Year
E1	CINAHL	Psychosocial Perspectives of the Partners of Breast Cancer Patients Treated With a Mastectomy: analysis of personal narratives[19]	Cancer Nursing	Hoga, Lak. *et al*	Brazil	2008
E2	CINAHL	Coming to grips with Breast Cancer: The spouse's Experience with His Wife's First Six Months[20]	J Psycosoc Oncol.	Zahlis, H; Lewis, M.	United States of America	2010
E3	CINAHL	Engaging Hope: The Experiences of Male Spouses of Women With Breast Cancer[21]	Oncology Nurse Forum	Duggleby, Bally, J; Cooper, D; Doell, H; Thomas, R.	Canada	2012
E4	CINAHL	Men's Perspectives on Individual and Family Coping With Their Wives' Breast Cancer and Chemotherapy[22]	Western Journal of Nursing Research	Hilton, BA; Crawford, JA; Tarko, MA	Canada	2000
E5	CINAHL	Exploration on the family's role and strengths after a young woman is diagnosed with breast cancer: views of women and their families[23]	European Journal of Oncology Nursing	Coyne, E; Wollin, J; Creedy, DK.	Australia	2012
E6	CINAHL	Meaning of family care to mastectomized women[24]	Rev. Escola Enf. Anna Nery	Fernandes, AFC; Silva, RM; Bonfim, IM; Barbosa, ICFJ; Araújo, IMA; Santos, MCL.	Brazil	2012
E7	CINAHL	African American couples merging strengths to successfully cope with breast cancer[25]	Oncology Nursing Forum	Morgan, PD; Fogel, J; Rose, L; Barnett, K; Mock, V; Davis, BL; Gaaskins, M; Davis, CB.	United States of America	2005
E8	CINAHL	Couple's experiences of breast cancer in Korea: a descriptive qualitative study[26]	Cancer Nursing (Lippincott Williams & Wilkins)	Chaeweon C; Eunkyung H.	Korea	2012
E9	CINAHL	The information concerns of spouses of women with breast cancer: patients' and spouses'	Journal Advanced Nursing	Rees, CE; Bath, PA; Williams ML.	England, UK	1998

		perspectives[27]				
E10	CINAHL	African American women with breast cancer and their spouses' perception of care received from physicians[28]	The ABNF Journal	Morgan, PD; Barnett, KP, Fogel, J; Underwood, SM; Gaskins, M; Davis, CB.	United States of America	2006
E11	CINAHL	Ambiguity and uncertainty: the ongoing concerns of male partners of women treated for breast cancer[29]	European Journal of Oncology Nursing	Harrow, A; Well, M; Barbour, RS; Cable, S.	Scotland, UK	2008
E12	PUBMED	Coping strategies among couples adjusting to primary breast cancer[30]	Journal of Psychosocial Oncology	Picard L; Dumont S; Gagnon P; Lessard G.	Canada	2005
E13	PUBMED	Hong Kong families and breast cancer: beliefs and adaptation strategies[31]	Psycho-Oncology	Simpson, P.	Hong Kong	2005
E14	PUBMED	Relationship vulnerabilities during breast cancer: patient and partner perspectives[32]	Psycho-Oncology	Fergus, KD; Gray, RE	Canada	2009
E15	PUBMED	Breast cancer in young families: a qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer[33]	Psycho-Oncology	Forrest G; Plumb C; Ziebland, SA.	Oxfordshire, UK	2009
E16	PsycINFO	Family support for native Hawaiian women with breast cancer[34]	J. Cancer Educ.	Moukuau, N, Braun, KL.	Hawaii – Honolulu	2007
E17	PsycINFO	Family support of immigrant Punjabi women with breast cancer[35]	Fam Community Health	Balneaves, LG; Bottorff, JL; Grewal, SK; Naidu, P; Johnson, JL; Howard, F.	Canada - Vancouver	2007
E18	EMBASE	Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners[36]	Cancer Nursing	Lopes, V; Copp, G; Molassiotis, A.	Australia	2012

Only seven (7) studies explicitly had the theoretical foundation used; we identified the Grounded Theory (which seeks to understand the reality from the perception, or the meaning of a context, or even of an object for the individual, producing knowledge, increasing understanding, and providing significant direction for the action (37). Phenomenology (38), which investigates other people's subjective experiences, i.e, aiming at seeing the world through another person's eyes, finding out how this person interprets his/her own experiences. Ethnography (39), defined as the study of the human interaction, and of the communities, through the direct participation, and observation of the researcher in the community studied; five (5) other studies based their discussions in concepts such as suffering, liminarity, and hope. The theoretical foundations and concepts used are compatible with the Medical Anthropology; and were used in situations similar to the families' experience, whether to explore the phenomena experienced, their behaviors, feelings, or still attitudes derived from common sense.

As for the objectives, six (6) studies sought to investigate specifically the spouse's experience, six (6) focused on the couple, and the other six (6) studied the nuclear and/or the extended family.

The senses described the processes experienced, from the data codification, with the ideas and actions of the experience being perceived as common or valued, explained by reasons and justifications, integrated by the themes: *the family amid the chaos caused by the disease; common sense and the stigma related to cancer in the perspective of the families; emotions and reactions present in the family during the course of the disease; joining of forces: family's* *attitudes and strategies regarding the caregiving experience.*

In the theme "*the family amid the chaos caused by the disease*", the impact of the disease produced needs in the families who participated in the study, being classified as the senses described as follows: understanding of the health/disease process, care-providing information/ knowledge, interaction with the team, need for self-care (Table 2). Some excerpts of the studies were transcribed and included in this review, retrieved from personal narratives to exemplify how the family members showed their needs. It is noteworthy that all the studies reported approval by the respective ethics committees for the development of the research.

Table 2 - Synthesis of families' needs regarding the caregiving experience grouped by attributed senses. Ribeirão Preto, SP, Brazil, 2014.

UNDERSTANDING OF THE HEALTH /DISEASE PROCESS	*The worst moment is when she is upset, and I can´t do anything about it.* (E2) *Nobody is prepared for a situation like this until it happens. You want to do something about it... get rid of it... this was the hardest part. You are powerless...* (E4 spouse) *I thought it would never happen to someone in my family...* (E6)
CARE-PROVIDING INFORMATION/ KNOWLEDGE	*The worst thing is not knowing what to expect. We're not prepared. Information is never too much!* (E4 spouse; E6; E8 spouse) *We searched on the Internet... We quickly accessed each piece of information that could help us make the decisions, and do the right things. (E7 spouse)* *You want information, because you want to know what is going on, and how it is affecting your wife and what you can do to help...* (E12) *Printed information, books, brochures, and booklets... it could be a secondary source of information. Your physician has to be the first.* (E12)
INTERACTION WITH THE TEAM	*I think there was a lack of information and awareness. When I went to Hospital X, nobody spoke to me... there were no professionals there.* (E12) *If only the physician or the nurse that cares for the breast came up to you and said: Well, you know that after the surgery your wife won´t be able to iron your shirts for a week....* (E12)
NEED FOR SELF-CARE	*I was confused, desperate. It was a shock, I felt as if my world was ending. The news were traumatic. I lost the motivation to work, and do things.* (E1spouse) *I feel as if I were on duty... 24 hours. I go to work and think of her* (spouse) *for 8 hours (during work), to get back home.* (E2 spouse) *I need time to read and pray, only for myself.* (E8 spouse)

In addition to the difficulties to understand and to accept cancer, evidenced in E6, other needs were identified in the studies, among them, we point out the lack of information on the disease, the treatments, their adverse reactions, the appropriate care management, and the lack of familiarity with the Health System. The needs increased the stress, and showed the insecurity and unpreparedness to provide care, interfering in the confidence for decision-making and care delivery. These were the recurrent elements in the narratives, in addition to the desire for information on the diagnosis, prognosis and life expectancy of the women, according to the narratives presented in Figure 2. (E4, E6, E7, E8, E12)

The fragility in the interaction among patients, family members, and healthcare professionals was identified as negative by the families. They mentioned a lack of opportunity to receive information, clarify doubts, and take part in the decision-making concerning the woman's treatment (E2, E12). Four studies (E1, E2, E4, E8) identified the need of the family members to care for themselves.

The common sense and the stigma of the disease

The families attributed the cancer occurrence to common sense situations exemplified with anxiety, lack of a healthy lifestyle, in addition to a high stress level. The suffering related to the stigma of cancer was described as prior to the treatment; in the diagnostic process, a number of signals were identified and related to the disease. Thus, the families had difficulties accepting the diagnosis, limitations related to the appropriate manner to care for the women and for themselves.

Emotions and reactions present in the family during the course of the disease

E8 presented seven (7) categories of reactions and feelings, identified by the researchers in the reports of the participant couples facing the cancer diagnosis: *Feeling shocked; feeling insecure as to what to do; blaming oneself or one's spouse for one's own ignorance; accepting the reality;*

wondering 'why me'? Holding in and hiding; doing something about it. These categories evidenced expressions of emotions that were present in the participants' lives.

The suffering was composed of a variety of feelings/emotions clearly seen in the family members: despair, anguish, hopelessness, isolation, depression, shock, anger, sadness, emotional distress, confusion: *I became sad... I felt confused...* (E1) The verbal and non-verbal manifestations presented were: shock, uncertainty, fear, discontentment, exhaustion by the overload of activities, and concern about the future, which brought suffering and imbalance, compromising the maintenance of the course of the family life. (E2, E4, E6)

Over time, the families began a process of understanding the reality, different from the one that was culturally understood – cancer as a synonym of suffering and death - *the stigma of cancer*. Hence, the need of adjustment in order to move on. As a result, the initial senses were being replaced by coping strategies, giving way to hope.

Joining of forces: family's attitudes and strategies regarding the caregiving experience

Throughout the experience, the families became aware of the needs of adjustments in their lives, revision of concepts, roles, and setting up of attitudes to better understand the health/disease process, attainment of information to provide care, better and greater interaction with the healthcare team, in addition to the need of self-care.

Three categories of strategies for resuming the normality, and moving on with the families' lives during the experience of caring for the woman were identified: *spirituality and religiosity; having hope and being positive; adjustment*, displayed in Table 3.

Table 3 - Strategies and ways of thinking of the families participant in the studies, and their respective narratives. Ribeirão Preto, SP, Brazil, 2014.

Actions/strategies/ attitudes	Narratives of the participants in the studies
Spirituality and religiosity	*The Lord enlightened us and gave us strength to cope with the worst*. (E1spouse). *The Lord watches over me, my wife, and my children*. (E3 spouse) *I don't know, but I think these drugs don´t do any good. I keep praying over her [...] Sometimes I feel like taking her out of here [...] treat her with tea and prayers...* (E6 Family member 6) *We can use the 'laying on of hands' technique to send energy to the ill organ. She doesn't believe it, so I keep trying to do it through my thoughts [...]* (E6 Family member 9) *"We prayed with our children; I think our family relationship became stronger because of this". (*E7)
Having hope and being positive	*I think every day that I get up there´s still hope. There are several types of hope [...] it changes all the time; it´s defined by what happens at that moment.* (E3spouse). *I think that the most important thing is to look at the positive side of things, and not to panic too much. Depression doesn't help treat cancer, but being positive is very important*. (E13 family member) *Have positive thoughts. With a positive mind and faith, you will move on.* (E17 family member).
Adjustment: Change in roles; taking over of housework; balance; change in the couples' relationship; joining of forces	*Because of her illness, I help with the cleaning, and sometimes I massage her hands, feed her. We have sat together more, and have talked more. There´s more communication.* (E13 husband) *I became the mom and she became the child. She became very dependent on me*. (E16 family member) *I do the housework because my wife can´t have any stress. There was pain and suffering, but cancer has made us think about our relationship and our family... Of course it would have been much better if it hadn´t happened.* (E8 spouse) I don't see it as her crisis or mine; the illness is something we cope with together, as a team. Cancer has been a mutual enemy that both of us has had the chance to spend a lot of time talking about, and feeling each other's feelings. (E2 spouse) *I want to give her whatever she desires, even if it means selling the house... I will give her as much comfort as possible*. (E8 spouse)

Spirituality and religiosity strategies
We observed that spirituality and religiosity are conceptual categories developed by the researchers of the analyzed studies (E1, E3, E7).

Studies have also recognized the practice, and the value of complementary therapies to the conventional medical treatment, by patients with life-threatening diseases, such as cancer (E17). Among them, the families valued and used: religious belief, spirituality, religion and religiosity in the process of overcoming the difficulties during the course of the disease and treatment.

Having hope and being positive
Once the emotional distress was identified, having hope and maintaining positive attitudes were considered logics of compensation in adjusting to the difficulties, seeking balance again to maintain the continuity of life during the provision of care for the woman with breast cancer (E2; E3 E4; E8; E13; E17).

Being positive and hoping for the best (E4), acting with positive attitudes (E16) resulted in courage in face of the difficulties, strengthening of the entire family, enabling the best outcomes. They were important for *things to keep working well, to balance, to heal and to prevent the cancer recurrence* (E13). The family members had their minds always set on positive results: *I pray and hope everything is working out, you know? (E2).*

The adjustment to the experience
In stressful situations, the families also had the tendency to be disorganized (E6) often requiring changes in roles, tasks, and daily routines (E2, E5, E6, E8, E13, E14, E16), mainly among the spouses participant in the study (E2, E17). The adjustment needs were evident, initially due to stress, overload, fear, insecurity, thus, making the caregiving exhausting and ineffective. Throughout the experience, the initial needs gave way to the strategies developed by the families, showing the relevance of joining forces during the experience of caring for the woman with breast cancer. (E4, E7)

The family amid the chaos awakened to caregiving. The family searched for information, emotional support, was physically present, monitored, tried to take part in the decisions and in the treatment, cut down the working hours, or even obtain a leave, taking over the housework and childcare. (E5, E8)

Based on the cultural principles that determine the role of the man, contrary to what was expected, it could be verified that men and spouses, when taking over activities carried out by the woman, and reducing their working hours to be with their wives, considered the changes positive and meaningful to the couple's life: greater intimacy, effective communication, better understanding of the needs of the other, and improvement in the interpersonal relationship, resulting in the strengthening of the marriage (E1, E2, E4, E5, E8, E12, E14).

Discussion

The characterization of the participants in the studies was carried out differently by the authors of the publications reviewed, and it was generally disregarded in the presentation and discussion of results of the articles, hence, there is no contextualization of these data concerning the objectives in the respective investigations. There was also little information on the research team and its reflexivity, preventing a detailed assessment in the first domain of COREQ. The data collection in the research should always occur to meet pre-established goals. The information should have been explored in the light of the study objectives, and discussed based on the theoretical references proposed for each study. Reflecting upon the objective of this review, we considered unnecessary the exclusion of the studies, as the results had considered the necessary contents for the synthesis proposed for the families' experiences.

Some degree of negligence related to the theoretical and methodological aspects in the studies analyzed could be noted, both in the description and in the use, such as the theoretical reference definition consistent with the study proposal, use of concepts for better supporting the discussions, methods and strategies suitable to the theoretical references, and objectives of the studies. We included studies with different methodological approaches aiming at increasing the sample, since few used the same approach, and it is a feasible option, according to the authors that established the review method used. Metasynthesis is the interpretative integration of results, and when carried out with qualitative research, it can include studies derived from ethnography, phenomenology, grounded theory, among others that characterize studies of such nature (40).

After careful interpretative analysis of the results, the discussion of the established units of senses followed.

The family amid the chaos caused by the disease
In the studies analyzed, there was a predominance of the extended family, which is a new family reality that includes also other people connected by kinship, and by the relationship network, such as mothers, mothers-in-law, sisters, sisters-in-law, among others, in addition to the couple, and children, living in the same space, sharing the same rules and culture (41). Regardless the arrangements, the entire family suffers with the chaos caused by the diagnosis of a disease like cancer, thus the professional approach should include the family involvement.

In the anthropological perspective, the family can be defined as a group of people sharing a universe of symbols, values, beliefs and norms. It is the socializing space for the search of survival strategies (41). The families considered cancer as an enemy that brings up feelings and attitudes, often negative, which conceptually represents the stigma culturally linked to cancer. They reported moments of battle between *good and evil*, expressed in feelings and reactions, arising from common sense, during the course of the disease; they sought to achieve "victory" – healing– or at least the balance necessary to keep moving on.

The experience of an illness is defined as the thing that the human being perceives in the place he/she occupies in the world, and the actions he/she carries out (42). Accurate definitions not always apply to it, as there is a gap between what is lived, and what is defined and expressed in words (43). According to the results of this experience, shock was the most common immediate answer. In six other studies, the impact of the diagnosis, and the experience of cancer involved the whole family (E-29; E6; E-12, E-19, E-29), and the woman's suffering. (E-2)

Personal needs among family members enabled the identification of the related categories: shock in face of the cancer diagnosis, own life change in order to adjust to the need of caring for the spouse, lack of time for self-care, loss of quality of life due to sleep deprivation, fatigue/exhaustion, guilt for lack of knowledge/insecurity to provide care, difficulty to adjust work and housework, misery, suffering, frustration, stress, among others. These reported needs reflect that self-care is a need neglected by them, also by the healthcare team, who generally focuses only on the ill. This negligence can lead to health problems, preventing the family member to continue providing care, in addition to producing social isolation, and other repercussions in the family context (3).

The common sense and the stigma of the disease

By means of the common-sense beliefs, the families sought cognitive explanations for the causes of the disease. A Korean couple regarded '*living under a lot of stress*' as the cause of cancer (E8). In certain cultures, such as the Chinese, the couples considered their beliefs important, and attributed the disease to bad luck, or other situations, such as worry, stress, depression.

It can be observed that the cultural knowledge, expressed in the participants' speeches, does not always correspond to the medical model. In the socio-anthropological context, it can be verified that the cause and the disease itself take on different senses, because for each person it occurs in a different manner. When someone feels ill, and becomes aware of it, this person will seek explanations in his/her cultural knowledge for the symptoms, and attribute them senses, which are configured social historical and culturally, by means of reflections and interconnections(43-44).

Cancer is a disease that bears the cultural stigma of suffering and death. The stigma has perpetuated throughout history, in which aspects of the life of the ill and their families are affected by the illness and its repercussions during the treatments. In this context, war-fighting metaphors show the magnitude of the problem, the multifactorial and multi-causal nature of the entire family's commitment in the context 'coping with the possibility that she might not survive', has changed. Stigma means mark or scar that leads to a sort of moral flaw making a person an outcast to society (45-46).

The difficulties arising from the stigma of the disease had repercussions on the families' acceptance of the diagnosis, in the limitations regarding the appropriate manner to provide care for the woman and for oneself, perpetuating the relationship between disease and stigma.

For anthropology, emotions are symbolic strategies that articulate the interpersonal work and the moral universe. They are learned in the family context, and are a way to react and maintain the social order in the public space (47).

Different times and societies produce types of language of suffering, which are experimented in the body, i.e, embodied, to the extent that this is the locus of production and the updating of meanings (45, 48).

Joining of forces: family's attitudes and strategies regarding the caregiving experience

Family members developed strategies that reflected the logics of compensation for resuming the normality, and the joining of forces among family members was strong and significantly positive.

Logic of compensation is a strategy- and idea-generating practice in the social life, aiming at achieving normality, or life balance that is acceptable to people, when they go through experiences with external and/or internal demands such as cancer, its treatments and repercussions (17).

In the events and experiences of life, the cultural heterogeneity linked to life conditions manifests by means of strategies and interpretations (17).

Spirituality, religiosity, having hope and being positive strategies

Cancer threatens the sense of self, work and family integration. When the disease weakens the control of body and mind, and affects the person's daily routine as well, the pressing question of self-awareness becomes more immediate (48). Given this reality, many family members turn to spirituality and religiosity as a strategy for better control.

Spirituality is defined as the connection with a bigger reality, which gives life meaning, and is lived by means of the religious tradition, or increasingly in the western society, by means of meditation, nature or art. Religiosity is considered as a manifestation of the religious experience, of the experience of transcendence, experienced by people and groups, and expressed in its different individual and cultural manners (prayers, beliefs, parties, celebrations, symbols, rituals, rites, among others)(9,49). They are part of the western culture in view of the strong influence of the Christian colonization that brought along the religious practices, but is also present in certain eastern cultures.

Hope is also a way to maintain the positive expectation, usually linked to religiosity. It was mentioned by several participants of the analyzed studies as a strategy to overcome the difficulties arising from the situations imposed by the cancer. It is related to the expectation for something that one wants to achieve.

Often related to faith and other beliefs, that the participants of the studies reported having to overcome the difficulties, it could be observed that hope made the family members more positive in coping with the problems experienced along the treatment, as a result, it was considered one of the most positive strategies. Hope is a very dynamic concept. It is the action of expecting something that one wants or that one believes to be possible (50). It is a word related to expectation, also considered a synonym of trust, often related to faith. According to the Holy Bible, in the book of Hebrews *11:1: "... Now faith is the substance of things hoped for, and the sign that the things not seen are true."*

Hope is believing that one's desires or intentions are possible to happen. Whether it is based on reason or faith, the one who has hope considers that he/she is able to achieve something or reach a certain goal (51).

"Hope opens up as a horizon of the human existence in the present moment. Thus, it conveys peace and safety to the subject, because it testifies that there is a future for him/her. The sure existence of this future allows people to accept and take over, in a positive way, the present they live in"(52).

The adjustment to the experience

Caregiving is considered an innate ability of the human being. In the clinical practice, it could be observed that the representation of the woman's social role in society remains as the home- and family-care-provider, although today an external job was added to the equation. If the woman gets ill and needs care, it will generate a difficult adjustment process, requiring adjustments in the routine and role changes among the family members.

On the other hand, the man's social role as the head of the family and main provider of the financial support, specially in the western culture, was reaffirmed in studies with men from both western and eastern cultures. Taking over the housework and the childcare hurts the hegemonic rule of the family provider, in addition to the impact on his self-esteem and social life (17).

The ability to work gives meaning to life, and its representation is impregnated in the urban-industrial capitalist society. In this social group, work defines different conditions of the human being. For the man, being normal is key in performing roles; it has value for them, and for the society in general (17).

For the reasons exposed here, when analyzing the senses attributed to the family's caregiving experience, and reinterpreting these senses in the light of the medical anthropology, it can be understood that the central meaning of this experience is the maintenance of the course of life, which is built by the process of joining forces, in which the family members aim to understand the illness, the treatments, and the repercussions resulting from the adverse effects, and have adjusted to provide care to the ill woman (E4, E7), by means of elements learned in the social context, i.e., their culture. Along the course, feelings, negative emotions, doubts, uncertainties and insecurities are experienced, yet, the family seeks help and support of knowledge, initially in professional assistance to overcome situations arising from the treatment. By means of complementary practices, they develop strategies or logics of compensation that provide spiritual comfort, strengthening of trust, hope and courage to cope with the difficulties, to achieve balance, and to move on with the family life (E2, E4, E15, E17, E18).

Final considerations

The general aim of this metasynthesis was to synthetize the knowledge on the family experience in caring for the woman with breast cancer, by means of the medical anthropological theoretical approach. 18 articles were selected after the evaluation of 812 titles, using strict criteria, and the instrument COREQ.

The synthesis of the studies highlighted the main categories of the family experiences, which were described and discussed in the units of senses: *the family amid the chaos caused by the disease; common sense and the stigma related to cancer, in the perspective of the families; emotions and reactions present in the family during the course of the disease; joining of forces: family's attitudes and strategies regarding the caregiving experience.*

These senses revealed the complexity of the family experience in becoming a caregiver.

The families emphasized that, in general, they are not included in the professional assistance planning, nor have their own needs valued, however, in face of the difficulties, they sought to adapt to the situation and to achieve balance.

We developed as central meaning the *maintenance of the course of life by the process of joining forces.* Through it, we emphasize the importance of the strategies used by the families to overcome the difficulties in the different situations of the experience. Spirituality and religiosity were practices valued and used for the strengthening of the family. The strategies led to resignation and balance achievement needed for moving on with life.

Cultural differences were observed in the family involvement in caring for the woman with breast cancer. In the Brazilian context, despite the small number of studies found, and the professional practice observation, a greater difficulty of the families to organize themselves in order to provide care for the ill woman could be noted. As a result, divorce and overload of responsibilities for a single person that takes over the provision of care on one’s own. Unlike the cultural contexts of the studies included involving groups of Canadians, English, Chinese, Indian immigrants living in Canada, it seemed that the families, despite all the initial difficulties, were able to organize themselves and share the caregiving.

This metasynthesis aimed at expanding and deepening the knowledge, providing information for the healthcare professionals to understand the experiences, and the different ways of acting of the families of women with breast cancer. Therefore, it might contribute for these professionals to manage an inclusive approach with the families, sharing their needs, and making them fit to provide care with greater security, serenity, and trust, thus contributing for improving the caregiving.

We highlight the significant limitation throughout the development of this review, regarding the structure and content of the articles, in which important information for the analysis of the articles were not clearly presented. We indicate that there are few interpretative publications on the family’s experience, mainly among nurses and other Brazilian healthcare professionals. Among the categories that are little explored in the studies we point out: gender, children’s perspectives, unmarried partners, or ones that live in separate homes, and the resignification of the subjectivities for the caregiving by the healthcare team, which need to be considered in further studies.

References

[1] Ministério da Saúde (BRASIL). Instituto Nacional de Câncer José Alencar Gomes da Silva. Coordenação de Prevenção e Vigilância Estimativa 2016: Incidência de Câncer no Brasil / Instituto Nacional de Câncer José Alencar Gomes da Silva, Coordenação de Prevenção e Vigilância. Rio de Janeiro: INCA, 122p. 2015.

[2] Ramos BF, Lustosa MA. Câncer de mama feminino e psicologia. Rev SBPH. 2009;12(1):85-97.

[3] Anjos ACY, Zago MMF. A ressignificação da vida do cuidador do paciente idoso com câncer. Rev.Bras. Enferm. 2014;67(5):752-58.

[4] Tavares JSC, Trad LAB. Famílias de mulheres com câncer de mama: desafios associados com o cuidado e os fatores de enfrentamento. Interface – Comunic., Saúde, Educ. 2009;13(29):395-408.

[5] Carvalho CSU. A necessária atenção à família do paciente oncológico. Rev. Bras. Cancerol. 2008;54(1):87-96.

[6] Ministério da Saúde (BRASIL). SUS. Politica Humaniza SUS. Brasília. Jan. 2004. Available from: http://portal.saude.gov.br/portal/arquivos/pdf/doc_base.pdfhttp://portal.saude.gov.br/portal/arquivos/pdf/doc_base.pdf. http://portal.saude.gov.br/portal/arquivos/pdf/doc_base.pdf

[7] Rodrigues JSM, Ferreira NMLA. A experiência da família no cuidado domiciliário ao doente com câncer: uma revisão integrativa. Rev. Eletr. Enf. [Internet]. abr/jun.2011;13(2):338-46. Available from: http://www.fen.ufg.br/revista/v13/n2/v13n2a21.htmhttp://www.fen.ufg.br/revista/v13/n2/v13n2a21.htm

[8] Souza MG, Espírito Santo FH. O olhar que olha o outro... um estudo com familiares de pessoas em quimioterapia antineoplásica. Rev. Bras. Cancerol. 2008;54(1):31-41.

[9] Helman CG. Cultura, saúde e doença. Trad. Claudia Buchweitz e Pedro M Garcez. 4.ed. Porto Alegre: Artmed, 2003.

[10] Flemming K, Briggs M. Eletronic Searching to locate qualitative research: evaluation of three strategies. J. Adv. Nurs. Review. 2007;57(1):95-100.

[11] Barroso J, Gollop CJ, Sandelowski, M, Meynell J, Pearce PF, Collins LJ. The challenges of searching for and retrieving qualitative studies. West J. Nurs. Res. 2003;25(2):153-78.

[12] Noblit GW, Hare RD. Meta-ethnography: Synthesizing qualitative studies. Sage University Paper series on Qualitative research methods series 11, serie 11. Beverly Hills and London: Sage Publications, 1988.

[13] Paterson BL, Thorne SE, Canam C, Jilling C. Meta-study of qualitative health research: a pratical guide to meta-analysis and meta-ssynthesis. California: Sage; 2 Thousand Oaks, CA. 2001.

[14] Sandelowski MDS, Emden C. Focus on qualitative methods. Qualitative Metasynthesis: issues and techniques. Res. Nurs Health. 1997;20(4):905-23.

[15] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-357.

[16] Geertz C. A interpretação das culturas. Rio de Janeiro: Guanabara Koogan, 1989

[17] Costa MCS, Rossi LA, Lopes LM, Cioffi CL. The meanings of quality of life: interpretative analysis based on experiences of people in burns rehabilitation. Rev. Latino- Am Enfermagem. 2008;16(2):252-9.

[18] Langdon EJ, Wiik FB. Anthropology, Health and Illness: an Introduction to the Concept of Culture Applied to the Health Sciences. Rev Latino-Am de Enferm. 2010;18(3):459-66.

[19] Hoga LA, Mello DS, Dias AF. Psychosocial Perspectives of the Partners of Breast Cancer Patients Treated With a Mastectomy: analysis of personal narratives. Cancer Nurs. 2008;31(4):318-25. doi: 10.1097/01.NCC.0000305748.43367.1b.

[20] Zahlis EH, Lewis FM. Coming to grips with Breast Cancer: The spouse's Experience with His Wife's First Six Months. J Psychosoc Oncol. 2010;28(1):79-97. doi: 10.1080/07347330903438974.

[21] Duggleby W, Bally J, Cooper D, Doell H, Thomas R. Engaging hope: The experiences of male spouses of women with breast cancer. Oncol Nurs Forum. 2012;39(4):400-6.

[22] Hilton BA, Crawford JA, Tarko MA. Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. West J Nurs Res. 2000; 22(4): 438-459

[23] Coyne E, Wollin J, Creedy DK. Exploration on the family's role and strengths after a young woman is diagnosed with breast cancer: views of women and their families. Eur J Oncol Nurs. 2012;16(2):124-30. doi: 10.1016/j.ejon.2011.04.013.

[24] Fernandes, AFC; Silva, RM; Bonfim, IM; Barbosa, ICFJ; Araújo, IMA; Santos, MCL. Meaning of family care to mastectomized women. Rev. Escola Enf. Anna Nery.2012; 16(1):27-33.

[25] African American couples merging strengths to successfully cope with breast cancer

[26] Chung C, Hwang E. Couple's experiences of breast cancer in Korea: a descriptive qualitative study. Cancer Nurs. 2012;35(3):211-20. doi: 10.1097/NCC.0b013e31822a60db.

[27] Rees CE, Bath PA, Lloyd-Williams M. The information concerns of spouses of women with breast cancer: patients' and spouses' perspectives. J Adv Nurs. 1998;28(6):1249-58.

[28] Morgan PD, Barnett K, Perdue B, Fogel J, Underwood SM, Gaskins M, Brown-Davis C. African American women with breast cancer and their spouses' perception of care received from physicians. ABNF J. 2006 Jan-Feb;17(1):32-7.

[29] Harrow A, Wells M, Barbour RS, Cable S. Ambiguity and uncertainty: the ongoing concerns of male partners of women treated for breast cancer. Eur J Oncol Nurs. 2008;12(4):349-56. doi: 10.1016/j.ejon.2008.04.009.

[30] Picard L , Dumont S, Gagnon p, Lessard G. Coping Strategies Among Couples Adjusting to Primary Breast Cancer. Journal of Psychosocial Oncology. 2006; 23(2-3):115-135.

[31] Simpson P. Hong Kong families and breast cancer: beliefs and adaptation strategies. Psycho-Oncology. 2005; 14: 671–683.

[32] Fergus KD, Gray, RE. Relationship vulnerabilities during breast cancer: patient and partner perspectives. Psycho-Oncology. 2009; 18: 1311–1322.

[33] Forrest G, Plumb C, Ziebland S, Stein, A. Breast cancer in young families: a qualitative interview study of fathers and their role. and communication with their children following the diagnosis of maternal breast cancer. Psychooncology. 2009;18(1):96-103. doi: 10.1002/pon.1387.

[34] Mokyau N, Braun KL. Family support for native Hawaiian women with breast cancer. J Cancer Educ. 2007; 22:191-196.

[35] Balneaves LG, Bottorff JL, Grewal SK, Naidu P, Johnson JL, Howard AF. Family support of immigrant Punjabi women with breast cancer. Fam Community Health. 2007; 30(1):16-20.

[36] Lopez V, Copp G, Molassiotis A. Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners. Cancer Nurs. 2012;35(6):402-10. doi: 10.1097/NCC.0b013e318231daf0.

[37] Dantas CC, Leite JL, Lima SBS, Stipp MAC. Teoria fundamentada nos dados: aspectos conceituais e operacionais: metodologia possível de ser aplicada na pesquisa em enfermagem. Rev Latino Am Enferm. 2009;17(4):573-9.

[38] Capalbo C. Fenomenologia e Ciências Humanas. Aparecida: Idéias e letras. 2008.

[39] Pope, C.; Mays, N. Pesquisa qualitativa na atenção à saúde. 3. ed. Porto Alegre: Artmed. 2009.

[40] Sandelowski, MDS, Barroso, J. Sandbar Digital Library Project. Qualitative metassumary method [pag. na internet] Chapel Hill (USA): University of North Carolina at Chapel Hill School of Nursing; 2004 Available from: http://sonweb.unc.edu.sandbar/index.cfm?fuseaction=about#

[41] Falco VMG, Melchiori LE. Conceito de família: adolescentes de zonas rural e urbana. Ed. Unesp. cap. 6. in VALLE, TGM., org. Aprendizagem e desenvolvimento humano: avaliações e intervenções [online]. São Paulo: Cultura Acadêmica, 2009. 222 p. Available from SciELO: Books <http://books.scielo.org

[42] Minayo MCS. Análise qualitativa: teoria, passos e fidedignidade. Ciência & Saúde Coletiva. 2012;17(3).

[43] Czeresnia D, Maciel EMGS, Oviedo RAM. Os sentidos da saúde e da doença. Rio de Janeiro: Editora Fiocruz. 2013.119p.

[44] Minayo MCS, Coimbra Jr. CEA. orgs. Antropologia, saúde e envelhecimento [online]. RJ: Editora Fiocruz, 2002. 209 p. ISBN: 85-7541-008-3. Available from SciELO Books <http://books.scielo.org>.

[45] Kleinman A. The illness narratives: Suffering, Healing, and the Human Condition. Basic Books, 1988.

[46] Goffman E. Estigma: notas sobre a manipulação da identidade deteriorada. RJ: Zahar, 1980.

[47] Lutz C, White GM. The anthropology of emotions. Ann. Rev. Anthropol. 1986;15:405-436.

[48] Peteet JR, Balboni MJ. Spirituality and Religion in Oncology. CA Cancer Journal for Clinicians. 2013;63:280-289.

[49] Van Ness PH. Spirituality and the Secular Quest. New York: Crossroad: 1996.

[50] http://www.significados.com.br. Dicionário de significados

[51] http://conceito.de/esperanca Conceito de Esperança. Acesso em 27/06/2016.

[52] BELLOSO, J. M. R. Esperança. In: Dicionário de conceitos fundamentais do cristianismo. São Paulo: Paulus, 1999, p. 227.