



# DESK REVIEW

'Cancer during pregnancy: its influence on the woman wellbeing and the mother child relationship'

## Abstract

analysis of resources that contribute to the patient's ability to cope with the diagnosis and treatment plans; strategies for empowerment; strategies and treatments to maintain a parental role and to function as "good mother"; strategies and treatments for promoting mother-baby bonding

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## Introduction

Cancer during pregnancy is considered to be a rare condition as it occurs in 1/1000 – 1/2000 pregnancies and the incidence seems to increase as women tend to delay childbirth to a later age.

Breast cancer, hematologic cancers, melanoma, and cervical cancer are the most frequently diagnosed malignancies during pregnancy (DE HAAN et al; 2018). The incidence of these cancers is not higher in the pregnant versus nonpregnant population.

Knowledge about treatment has progressed in recent years with improved maternal and neonatal outcomes. The number of women who decide to continue their pregnancy and undergo cancer treatment is increasing. Treatment and care of pregnant cancer patients should adhere the standard cancer treatment and studies have shown that termination of pregnancy does not improve survival.

Pregnancies complicated by a cancer diagnosis should therefore be treated as high-risk pregnancies and require a multidisciplinary approach from well-trained professionals in specialized referral centres.

However, cancer in pregnancy poses complex clinical, psychological, and ethical challenges not only for the medical team but for all health professionals working in this field.

This report consists in a result of a desk research based in using already existing data in three different area: emotional wellbeing of women, coping strategies and **communication skills/integrated approach**. Existing data have been summarized and collated to increase the overall effectiveness of research and make them more accessible to all health care professionals. As the report shows, there is limited evidence about how pregnant cancer patients experience the cancer-related and maternity care they receive or whether it meets their needs.

Although several authors consider cancer to be a 'critical life event', studies that address the psychosocial implications of cancer in expecting mothers are scarce. There are no studies addressing the possible negative impact of a cancer diagnosis during pregnancy on the mother-child relationship and on the child's development.

At the same time, partners believe in normalization of pregnancy also for these women. Normalisation means a positive experience of maternity despite challenges and risk factors. Partners believe that there are some international recognized practices that must be applied to all women in order to fulfill their expectation of a positive pregnancy. Each mother/child couple needs its own equilibrium, without preconceptions and with the help of the internationally recognized “best practices” guide (Prosperi at, 2020).

These expectations include the birth of a healthy baby in a clinically and psychologically secure environment, coupled with the continuity of practical and emotional support on the part of the companion and the availability of a competent and gentle healthcare team. All women wish for a respectful maternity assistance, one that guarantees dignity, privacy and confidentiality, an informed choice and continuous support throughout labor, delivery, and nursing.

When women speak of birthing normality, those who desire it particularly are the ones who are living a pregnancy while being affected by oncological pathologies. Having experienced their own “body’s betrayal”, these women will undoubtedly find it more challenging to have a normal pregnancy experience. They will first have to “make peace” with their own body in order to take care and tune in to the needs of their child (Prosperiat al; 2020).

## Method

Desk research is a research method that involves using already existing data. Existing data is summarized and collated to increase the overall effectiveness of research.

Partners’ researchers searched for PubMed and EBSCO articles in English, published between 2005-2020 using search terms: cancer and pregnancy, psychological impact, emotional wellbeing, coping strategies, bonding, motherhood.

**A systematic review has been implemented: identify, evaluate (in terms of..), and summarize the findings of all relevant individual studies over our health-related issue, will make the available evidence more accessible to decision makers and research too.**

Partners have agreed on focus the desk research on three main areas:

The partners of the PosMat project with their own professional expertise and different background organized meetings and online-meetings to discuss the topics mentioned above before arriving to the final version of the report.

## Management of cancer in pregnancy

*Medical guidelines?*

### Area 1: Emotional well-being of pregnant women diagnosed with cancer during pregnancy

Cancer diagnosis during pregnancy is an unexpected and hard challenge that involves a growing number of women, mainly because recently the delaying of maternity has become increasingly widespread. If on the one hand there are a significant number of studies about medical cancer management during pregnancy, on the other hand studies about psychological implications and emotional wellbeing of pregnant women diagnosed with cancer during pregnancy are fewer.

#### 1.1 Levels and types of distress and concerns

Particularly, authors underline a huge amount of concerns in women with cancer in pregnancy as worries for prognosis, for changes in body image, sexuality, fertility, and generally in the family system; sometimes pregnant women experience transitions from shock and anxiety, sadness and hopelessness, anger, guilt or shame toward a sense of relief (after a period of diagnostic uncertainty), sense of challenge, acceptance (Alder & Bitzer, 2008). A popular study investigated the determinants of long-term distress in these conditions and it concluded that women involved in that research were at higher risk of experiencing long-term distress if they had not received fertility assistance, if they had been advised to terminate their pregnancy, if they had undergone a caesarean delivery, if they had had a preterm baby, if they had not produced enough milk to breastfeed, if they were currently experiencing a recurrence, and/or if they had undergone surgery post-pregnancy. This study underlies that distress during pregnancy is a risk factor for adverse outcomes like preterm birth, low birth weight, neurodevelopmental impairments and mother-infant attachment problems (Henry et al., 2012).

Another study investigated the levels of distress of couples in which the pregnant women had cancer and the relationship between their coping strategies and psychological distress (Vandenbroucke et al., 2017). Participants mainly using internalizing emotion regulation strategies had significantly higher levels of distress

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and concerns than those who used positive coping strategies or searched for someone to blame. Surprisingly, participants who mainly searched for someone to blame for their problematic situation had the lowest levels of concerns and distress. One hypothesis is that these women and partners denied or avoided their emotions and thoughts and therefore reported low levels of concerns and distress.

Another kind of concern within women with cancer in pregnancy is about the possibility to harm their unborn child and the sense of guilt in relation to their identity as good mothers, to breastfeeding (when it wasn't possible) and to the health of their children. Frequently these women fear for their children's development, particularly if they have undergone treatments during pregnancy, and they fear of not being able to handle a baby (Ives et al., 2012).

The most important and current issues pertaining to psychological aspects and conditions are mainly focused on the maternal prognosis followed by the effects of the therapy on the foetus and the risk of continuing with the pregnancy. Emotional states as an integral part of the psychological state of these patients are not less important. Apart from anger, grief, anxiety, sadness, and fear, psychological troubles include:

- concerns regarding foetal survival and pregnancy outcomes;
- after dealing with problems associated with pregnancy, concerns about body and sexuality, loss of fertility, premature ovarian failure, and future childbearing;
- uncertainty and insecurity about a relapse of the disease as well as the socioeconomic consequences that can lead to stress related to losing a career or dismissal from the workplace.

A recent study focused on major themes such as (1) experiencing a clash of priority between baby's life and mother's life, versus mother feeling in alliance with baby; (2) having perceptions of being physically and emotionally saved by the pregnancy and baby; and (3) experiencing a loss of being a mother (Zubor et al., 2018).

## *1.2 An analysis of cognitive and emotional processes*

Cancer and pregnancy is a jarring binomial that, when present, activates many processes in the pregnant women and their partners. Some studies refer to the importance and the difficulties of the decision-making process in this condition (Harrison, 2013).

There are many factors that may influence the decision making process: some of them are inside the woman, as the thought that the final decisions will involve at least two individuals, the mother and the foetus; or, for example, to have or not other children: generally, for the mothers who have other children, the priority is to receive the best treatment so that they could survive as long as possible; for the women

who are pregnant for the first time, generally the priority is to protect the life of their unborn child. Other factors that may influence the decision making are external: the level of the communication's clearness by the medical staff; the physician's advices and relative potential conflicts with the woman's perspective; the partner's opinions and the family members' concerns; the woman's and couple's fears and concerns (Alder & Bitzer, op. cit.; Ives et al., 2012.; Harrison, 2013; Ferrari et al., 2018; Faccio et al., 2020).

Frequently, the decision-making process is associated with decision making conflicts that affect all the subjects involved in this tricky condition. In fact, the woman experiences the conflict between the joy of being pregnant and the threat of illness and death; furthermore, she experiences the conflict between the concern for the safety of her unborn child and the concern for her own health. The partner often wishes his child will be born, but at the same time he wishes his partner will live<sup>1</sup>; he has to understand if he feels prepared to possibly grow a child without a partner. Other conflicts may be inside the physicians when they have to safeguard both the benefit of the mother and the benefit of the child, indeed sometimes there is a conflict between the maternal autonomy and the doctor's obligation for the child's benefit (Zanetti-Dällenbach et al., 2006) and other times there is a conflict of fetal benefit between the mother and the doctor, then the mother wants to protect his unborn child while the doctor advices to terminate the pregnancy. Some studies report the difficulty to obtain information about other options if the patient did not agree with the advice of a doctor, and to deal with young male doctors who could not relate to the women's situation of giving birth (Kozu et al., 2020).

A recent Japanese study (Kozu et al., 2020) adds that decision-making in pregnant women with cancer may be also conditioned by the verbal and nonverbal communication between the women and their family members, by the confrontation with dilemma and uncertainty, and even by the redefinition of the women's own decisions, that continues after they made a choice. Particularly, with regard to the communication with family members, the literature states that when communication among women and their families members is poor, the pregnant women experience a sense of solitude and anxiety, and a loss of power to convey their thoughts to their families. Indeed, for many women the fetus' life is important, but this remains obscure and subordinate in communication with their surroundings; women's families or friends often persuade them to prioritize themselves over their fetus or their fertility, but sometimes women do not interpret the advice to care for themselves as a positive message.

In fact, while many women reach firm decisions about their condition, both if they choose to continue the pregnancy or to terminate it or to undergo to the treatments before or after the delivery, etc., however sometimes women reach out to a redefinition of their decision, so that some woman who terminated her pregnancy experienced feeling of regret, because she did not have the power to ask doctors and family members for more time and information to make a decision (Kozu et al., 2020). In some other cases, when the woman

choose to go forward with the pregnancy, she has to start a necessary and arduous process of adjustment: as a pregnant, she makes a gradual transition to parenthood, from a first stage of uncertainty, physical discomfort and ambivalence to a final stage of active imagination and preparation to holding the child; as a patient, she has to experience an adjustment to her cancer, that is influenced by three main factors: disease-related factors, individual factors, sociocultural factors (Alder & Bitzer, 2008).

### 1.3 Prenatal attachment and construction of the parents-baby bonding

A gestational cancer is a condition of high-risk pregnancy, and then it exposes the pregnant woman and her partner to many risk factors from a medical, psychological and social point of view.

We've discussed about how to support the women's psychological wellbeing, but given that cancer during pregnancy may raise distress in women, it should take attention also to the potential negative impact on the mother-baby bonding and on the foetus' health: statistically, it is found that many children born of women who have experienced severe stress or anxiety during pregnancy, often present different problems: from ADHD to behavioural disorders, from aggression to extreme anxiety (Glover, 2011).

The woman's concerns about her motherhood and, at the same time, about her illness, make it desirable to offer split consultations: some time may be spent to talk about the pregnancy and other time may be spent to talk about the illness. It is important to prepare and anticipate the postpartum period, because probably the women will undergo adjuvant treatments and they will have no much time and not enough energy to spend with their newborn.

One of the most important issues, that however receives just a few attention, is the construction of the relationship with the baby, starting from the prenatal attachment until to the postnatal mother (and father) baby bonding. This aspect fades often into the background because of the right priority of the safety of life, but it should not be forgotten that high stress during pregnancy may affect the health but also the relationship between mother and baby.

No studies have been found about prenatal attachment in cancer and pregnancy, but there are some studies about this kind of relationship in a more general condition of high risk pregnancy, so we can and we should extend those findings to our topic.

A recent research investigated the parental prenatal attachment during pregnancies at risk for preterm delivery (Pisoni et al., 2016). Women with high risk pregnancy frequently experience fear, vulnerability, passivity. Specifically, using the Maternal and Paternal Antenatal Attachment Scales, it has been studied the quality of the attachment, as the affective experience toward the unborn child, and the intensity of the attachment, as the amount of time thinking or dreaming about and talking to the fetus. The study shows similar results in women and their partners and illustrates that high risk pregnancy couples had a parents' affective experience characterized by "distance, irritation, negative and unpleasant anticipation, and a vague internalized representation of the fetus".. These feelings may be temporary defense mechanisms from a possible child loss; but the consequence is that a low investment in the prenatal attachment may have a negative impact on the mother-baby bonding. This suggests the importance of evaluating the attachment of both parents in a high risk pregnancy, because this is very important for the couple and for the child development. These findings also suggest the relevance of a close collaboration between obstetrics-gynecology services and psychology-psychiatric services in order to an efficient healthcare of these couples. The just cited results are also consistent with another study that involved women with breast cancer during pregnancy, women with breast cancer before the pregnancy and pregnant women without any diagnosis, that underwent a semi-structured interview. The study shows that women with a diagnosis during pregnancy had mental representations of their children not well-defined and lacking in details, but at the same time they reported a huge desire to safeguard themselves and their children. Finally both the women with previous and current diagnosis of breast cancer reported a mix of feelings, like joy and worry, and experienced greater support from their partners compared to pregnant women without any diagnosis (Faccio et al., 2018).

Moreover, a Korean cross-sectional study was conducted to identify the factors that influence maternal-fetal attachment in high-risk pregnancies, and its findings reveal that factors as anxiety, multiparity, prenatal tests and dyadic adjustment influence the prenatal attachment. The most influential factor in the study was anxiety: particularly anxiety was negatively correlated with maternal-fetal attachment, so while dyadic adjustment within the couple was positively correlated with maternal-fetal attachment. That means that it is important to improve healthcare interventions aimed to decrease anxiety in women with high-risk pregnancies and to enhance prenatal attachment through conjugal harmony (Hee & Young, 2015).

Another study shows that women involved in the sample who had low risk pregnancy experienced higher levels of prenatal attachment than other women with high risk pregnancy, and this is consistent with most of the previous research findings (Eswi & Khalil, 2012).

For the sake of completeness, it should be noted that some study shows that although the perceived stress increases in high-risk pregnancy it does not have necessarily a negative impact on the prenatal attachment<sup>16</sup>,

however the majority of the literature refers to a prevalence of negative relation between high risk pregnancy stress and prenatal attachment. It is also known that sometimes women with cancer during pregnancy refer that they find it difficult to dedicate enough time to the construction of a prenatal relationship with the fetus and they often fear that they will not be good enough mothers, because of the time and the energies to spend in treatments after the delivery (Faccio et al., 2020).

It also should be noted that pregnancy is the time of construction of the mother-child relationship, especially from the 2<sup>nd</sup> trimester, when the mother perceives for the first time the unborn-child's movements, but "if this developmental task is not accomplished, both the mother and her child may experience poor emotional adjustment and may encounter significant difficulties in the establishment of the mother-child relationship after birth" (Ferrari, Faccio, Peccatori, Pravettoni, 2018). This confirms the importance of a support for maternal-fetal attachment comparable to women with high levels of depression during pregnancy. Sonographies, palpation, 3D ultrasound and techniques of guided imagery may be used to facilitate the mother-fetus bonding and the maternal representations of the unborn-child.

Furthermore many recent studies conducted in the field of prenatal psychology demonstrate that the fetus is not a passive being, but he actively participates in the relationship with her mother. There are some prenatal care programs (e.g. Prenatal University, Prenatal Bonding, ...) that show many fetus' competencies, like an early ability to recognize the parents' voices and to specifically react to their simulations. These programs facilitate prenatal attachment during pregnancy: e.g. Prenatal Bonding is a path that involves both the parents and possible siblings in developing an early relationship with the fetus. Some studies show many positive outcomes, e.g. less pain during delivery thanks to better cooperation between mother and child, a deeper mother-child attunement, an easier transition to regular sleep patterns in the postnatal period (Schroth, Eichhorn, 2013).

It should be noted that in the specific condition of cancer during pregnancy, the woman's resilience may influence the prenatal attachment and the woman's own mood states. In fact, an Italian pilot study revealed that the woman's resilience correlates positively with the prenatal attachment and negatively with the mother's negative mood states; moreover social resources may influence the intensity of the attachment between mother and fetus. These findings suggest the importance to assess and improve the woman's resilience and the family support when cancer in pregnancy (Bonassi et al., 2018).

### 1.3.1 Postpartum and breastfeeding

It is well known that the postpartum phase is prepared during the pregnancy period. For women with cancer during pregnancy, the postpartum is often a period in which they have to undergo some surgeries, invasive chemotherapy or radiotherapy and other treatments; then it's a complex phase that may be perceived in a particularly negative way, if also the pregnancy has been lived with negative mood states. A research reveals that women who had experienced depression, anger and anxiety during pregnancy, referred a lower physical and psychological perceived quality of life during the postpartum period (3 months after delivery); women who expressed higher level of fatigue, confusion, hypervigilance and hyperarousal during pregnancy reported a lower psychological perceived quality of life during the postpartum. Finally, with regard to the mother-baby relationship, it should be noted that when the women had experienced post-traumatic symptoms of intrusiveness during pregnancy, three months after the delivery they had a greater tendency to perceive their children with a difficult temperament, they were more at risk of dysfunctional parenting and experienced higher levels of parental stress (Faccio et al., 2019).

These findings suggest the importance of not leaving out the psychological wellbeing of the woman during pregnancy, because of his impact on the future mother-child relationship.

In this regard, another relevant theme is that of breastfeeding, a postpartum task that has not only an individual relevance but also a socio-cultural significance (Rees & Young, 2016). Many women worry that no breastfeed may have a negative impact on their relation with the newborns; sometimes these women report difficulties with the transition from breast to bottle feeding when they must undergo chemotherapy (Ives et al., 2012). It seems that a possible lower milk production due to the treatments, may have the effect to increase the distress in women wishing to breastfeed (Henry et al., 2012). This is consistent with the results of a recent study that investigated the differences between different ways of breastfeeding in women with cancer history and healthy women and that valued the link between the type of breastfeeding and the women's distress. The findings reveal that women with a previous or current history of cancer were less inclined to breastfeed with their own breast, compared to women of the control group. Particularly it seems that there is a correlation between the woman's confusion (assessed with the Profile of Mood States subscale) and the type of breastfeeding. The tendency of the women with cancer to experience higher levels of psychological distress could be caused by the absence of clear and specific guidelines about breastfeeding after or during cancer (Bonassi et al., 2019).

## Area 2: Cognitive coping strategies of women and partners confronted with cancer during pregnancy

In this section we will analyse studies with regards of:

- The quality of the relationship with partners;
- Analysis of resources that contribute to the patient's ability to cope with the diagnosis and treatment plans

### 2.1 The quality of the relationship with partners

The literature shows that having a partner and the quality of this relationship makes an important contribution to coping with the cancer diagnosis. Bultmann et al. (2014) found that people who need psychosocial support after cancer often do not have a partner, which instead can act as a support figure during the difficult period after diagnosis. Particularly, in conditions like a Gestational Breast Cancer, it's important the protective role, support and care of the partner and the common fighting spirit as a couple. It seems really healthy for the pregnant woman with cancer to perceive her own partner as the baby's father, within a triadic relationship (Faccio et al.); it may be a protective factor considering that the literature refers that mothers with cancer have more intrusiveness in intimate life domains (Arès et al., 2014). Regarding the perceived social support, some women report a decrease, others report no significant changes in social support of the partners over time, others report a mostly high partnership satisfaction

One of the consulted studies states that a current need for psychosocial support was more prevalent in survivors who were less likely to be employed, less often in a partnership, more often divorced or separated, more frequently diagnosed with stage IV disease, more likely to have a comorbid disease, and more likely to appraise their child as being distressed (Type I) compared to cancer survivors without expressed support needs and the total sample (Bultmann et al., 2014).

Families that were able to act openly, express feelings directly, and solve problems effectively had lower levels of depression and, at the same time, direct communication of information within the family was associated with lower levels of anxiety. Aside from differences anxiety due to cancer type, patients' illness characteristics appear to be risk factors in patients' but not relatives' depression and anxiety. These results suggest that researchers

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and clinicians need to be family-focused as cancer affects the whole family, not just the patient (Edwards & Clarke, 2004).

Individual levels of distress were determined more by gender than by the role of being the person with cancer versus that person's partner. The association between patient and partner distress within couples was only moderate but is sufficient to warrant further consideration of the notion that these couples react as an emotional system rather than as individuals. It is noteworthy that this association is not moderated by gender. With a general lack of comparison groups, the question of how much distress can be ascribed to the cancer experience cannot be answered decisively. Some attention needs to be directed toward factors other than cancer as direct influences of distress in these couples and to mediators and moderators of the cancer experience. Particularly, the focus should be on component relationship processes that affect the intimacy in 2 categories: 1) relationship enhancing, 2) relationship compromising.

The relationship enhancing processes include:

- reciprocal self-disclosure,
- partner responsiveness: feeling understood, cared for,
- relationship engagement: openness to discuss about cancer in relational terms, about changes with the partner (aspects that have changed or need to change), efforts to maintain components of the relationship that are important to either partner.

The relationship compromising behavior includes reduced marital quality and psychological distress, identifiable in three categories: 1) avoidance, 2) criticism, 3) pressure withdraw (Manne & Badr, 2008).

## 2.2 Analysis of resources that contribute to the patient's ability to cope with the diagnosis and treatment plans

Mothers with cancer have many fears. Some studies reveal that maternal age, age of children, time since diagnosis and level of parenting stress are potential determinants of perceived stress, illness intrusiveness and fear of cancer recurrence (Arès et al., 2014). This aspect needs attention by the healthcare professional, because of the influence of mother's health on the family system health.

Considering the well-known effect of the parents' wellbeing on the offspring's wellbeing, it's important to underlie that in this condition, maybe more than others, the coping strategies of the parents and the family functioning have an impact on the psychological wellbeing of the child (Faccio et al.). The coping strategies are oriented by many factors. For example, mothers who already had children have another viewpoint about the

treatment than women who are pregnant for the first time. The main concern of both is whether to take care for the baby/themselves (Ives et al., 2012).

This means that mothers with cancer need tailored psychosocial support in order to overcome the specific challenges faced during and after treatment (Kuswanto et al., 2018); moreover biological, personal, and most importantly social factors contribute to cancer patients' resilience and, consequently, to favourable psychological and treatment-related outcomes.

An interesting study showed that women and partners mainly using internalizing coping strategies had the highest levels of distress, compared with those using positive or blaming coping strategies. - women were more inclined to maintain the pregnancy than their partners. This is partly consistent with the literature, as women and partners in the positive coping cluster mainly use strategies that are labelled as "more adaptive" and thus are expected to have lower levels of distress. Women may use physiological, social or behavioural ways of emotional regulation and other: e.g. un-conscious cognitive processes are intertwined with cognitive emotion regulation. However, referring to the couple, the research shows that a higher stage of the disease at diagnosis was related to more concerns about the disease and treatment for women with breast cancer, but not for their partners. This study states that women diagnosed nowadays can thus be better informed about the safety and risks for their child, which may lower their level of distress (Vandenbroucke et al., 2017).

There are some interesting findings about the correlation between the Big Five Personality Factors and the coping strategies. For example, it seems that neuroticism was associated with negative affect, which was explained by avoidance coping strategies. Extraversion and neuroticism were associated with positive affect, and these associations were explained by approach coping strategies. Conscientiousness was more strongly related to positive affect directly and indirectly through approach coping strategies among older survivors than among younger survivors (You et al., 2018).

Considering the coping strategies another study investigated the avoidance levels among the patients and showed very interesting findings. Patients in the low avoidance cluster had significantly lower anxiety, than patients in the high general coping cluster; instead patients in the high avoidance cluster had significantly lower friendliness, and lower vigour, scores than patients in the high general coping cluster, they also had significantly lower friendliness scores than the low avoidance cluster patients. Negative affect, as measured by the true POMS (Profile of Mood States) total score, was significantly higher for patients in the high avoidance cluster in comparison to the low avoidance cluster (Hack & Degner, 2004). These findings reveal that high avoidance may lead the cancer patients to negative psychological outcomes and how it's important to sustain adaptive coping strategies. In fact, the ways in which one copes with a cancer diagnosis predicted significant variance, suggesting that the use of specific coping strategies at diagnosis may have long-term importance for meaning in life (Jim et al., 2006).

Another study shows that the most frequently used coping strategies were positive cognitive restructuring, wishful thinking, making changes. Qualitative analyses based on open-ended questioning of how women best coped with different stressful aspects of their diagnosis showed that women reported finding different strategies useful depending on the stressor. Social support was helpful in dealing with anger or depression, whereas positive cognitive restructuring was more helpful for concerns about the future. It's interesting to note that most coping strategies cited in commonly administered coping scales were used frequently by these women; however several coping strategies not generally measured were also deemed valuable, including engaging in physical activity, using medications, and resting (Manuel et al., 2007).

An interesting research revealed that quality of life scores of the involved cancer patients were within the average limits, despite 87.6% of patients being in an advanced cancer stage. Resilience correlated significantly with all quality of life components, whereas active coping did it only indirectly, via resilience: it confirms that resilience is a protective factor for the quality of life of these patients (Popa-Velea et al., 2017).

Investigating the relations between illness representations and coping behaviours (in particular between control perceptions, problem-focused coping, and cognitive reappraisal), some findings reveal small to moderate effect sizes, whereas random-effects models reveal moderate to large effect sizes between illness representations and illness outcomes (in particular between identity, consequences, emotional representations, and psychological distress). The narrative review of studies with insufficient data provided similar results (Richardson et al., 2017).

### Area 3: Counselling strategies for health professionals working in the field of cancer in pregnancy.

An overview of health systems performance and strategies in person-centred care in Europe, shows that all our national health systems underline the urgency to apply a person-centred approach (Policy briefing by Giuseppe Paparella; 2016.)

There is a growing body of evidence regarding communication, information sharing, decision-making, and patient-centred care in oncology in general. However, with pregnant women, health professionals also need to address pregnancy care and options.

Counselling pregnant women with cancer is an under researched topic. There are several case reports of cancer in pregnancy to demonstrate individual approaches and experiences, but they are not necessarily evidence based, who are instead in a limited number.

It has been made clear from the literature that health care professionals need formal training on communication skills to appropriately counsel pregnant women with cancer. **AUTHORS**

People with cancer, their families and carers have a high prevalence of psychological stress which may be minimised by effective communication and support from their attending healthcare professionals.

Research suggests communication skills do not reliably improve with experience (Philippa M Moore et al; 2013). Communication skills training is effective in changing healthcare professionals' behaviour in cancer care about communication and interaction with patients (Moore et al; 2013).

Additional research about the long term efficacy of communication skills training is needed, for example, examining 'compulsory rather than voluntary' training (Deborah K. Mayer) or about applying more experiential methods of teaching (designed to raise nurses' levels of self-awareness) (Susie Wilkinson; .....

## Communication skills of the multidisciplinary team

Cancer during pregnancy impacts two lives, the mother's life as well as the life of the unborn child. The ambiguity of a possible life-threatening disease in combination with the onset of new life presents a challenge in medical and psychological approach.

Receiving the bad news of a cancer diagnosis during pregnancy is often felt as an unexpected traumatic event, not only for the patient, but also for her partner and family. It causes conflicting emotions of happiness being pregnant and fear of death and hopelessness.

Breaking bad news should be performed by one or a few persons skilled in communication with a high biomedical and psychological competence. It is of utmost importance that patients get honest and accurate information from health care professionals.

### Guidelines for breaking bad news (A. Giris;1998)

- Assess the mentality of the patient and understanding
- Ensure privacy
- Take adequate time to assess the situation
- Be honest
- Provide accurate information
- Show empathy
- Arrange family members to be present

- Provide evidence-based treatment options
- Inform about supportive services
- Clearly indicate that the patient had the final decision regarding their care
- Briefly explain the process by which the diagnosis was reached
- Provide varied methods to convey the information, for example, written material, video, etc.

This issue is often enhanced by an unsuitable way to communicate of the medical staff, that makes more difficult the understanding and the decision making of the women and their partners. Indeed, the medical staff often communicates many information about diagnosis, treatments, surgery, etc., without considering the real patient's understanding and her need for time to realize the complexity of her own condition; sometimes the language employed to communicate is not clear and it's full of medical terms, very hard to understand (Alder & Bitzer, op. cit.);

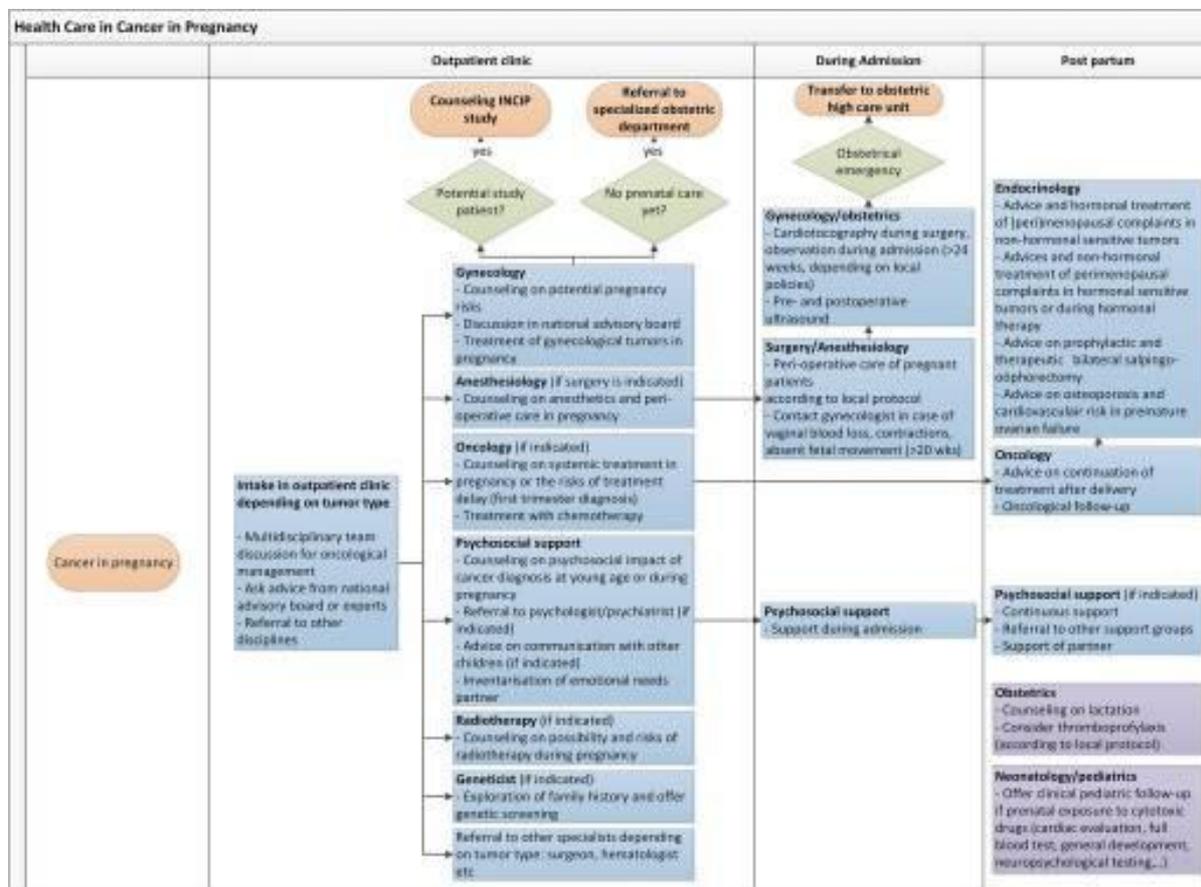
A realistic and honest approach is essential to maintain the patient's confidence and support and where possible, hopeful aspects appropriate to the patient's situation must be emphasized. Since most patients only recall limited parts of the information given, information should be given in pieces at several different appointments. Patient's understanding of her situation as well as the awareness of her prognosis should be assessed.

Since the complexity of a cancer diagnosis requires a multidisciplinary approach, it is important that patients experience the dialogue between different disciplines (oncology-obstetrician). Therefore, intermittent briefing sessions among the specialists, with or without the presence of the patient, are of utmost importance. It is helpful for the patient if they feel cared for as a mother-baby unit as a whole.

Though, the interests of obstetricians and oncologists are often competing in regard to the mother and her unborn child's health (Ives et al., 2012).

Creating a clinical care pathway for this specific patient group can be beneficial to support the multidisciplinary approach (Maggen et al., 2020)

In order to solve these issues, many studies identified some functional approaches, that may make less difficult the decision making process, because the decision reached has a huge importance for the psychological health of the woman (Alder & Bitzer, 2008; Ives et al., 2012.; Henry et al., 2012; Ferrari et al., 2018; Faccio et al., 2020).



## Strategies for empowerment

Empowerment means “the process of becoming stronger and more confident, especially in controlling one's life and claiming one's rights.”

Health professionals should welcome and support a woman's emotional needs with empathy, participation and active listening, to encourage, reassure, respect her choices, facilitate the identification of her own needs, and to promote empowerment rather than dependence (Proserpio et al; 2020).

Counseling pregnant cancer patients regarding empowerment should be patient-centred with respect to the patient's concerns, values, cultural background, beliefs, ideas, wishes and priorities in life in order to facilitate shared decision-making. It is important that patients are well informed about their prognosis and in case of poor prognosis, the option of a termination of pregnancy needs to be discussed. A cancer diagnosis affects not only the patient but a whole family. Patient's partner and family have an active role in the decision-making process and should therefore be involved in these discussions.

Shared decision-making could be beneficial for patient satisfaction as well as clinical outcome. It comprises four key characteristics (Karunaratne, K et al., 2012):

1. at least two partners involved
2. both partners take steps in sharing a treatment decision
3. both partners share information about treatment options
4. together they arrive at a consensus regarding the preferred treatment option

Maternal exposure to stress during pregnancy might cause adverse outcomes, such as preterm labour, low birth weight neuro-developmental impairments and disabilities (Hobel CJ et al., 2008). Creating a bond of trust and providing confidence can reduce stress levels for the patient and her family.

The organization of patient support groups, online forums, non-profit organizations might increase the awareness of the occurrence of cancer during pregnancy and might help patients in finding support in different fields: medical, emotional, financial, etc.

It is recommended to advise women to take part in birth groups and in breastfeeding mothers self-help groups, guaranteeing that privacy and confidentiality are always maintained. Although unevenly organized across our country, there is no doubt about the strategic importance of such groups in offering moments of normality. Being around other mothers helps a woman with a neoplasm feel closer to problems that are more common (Prosperi et al., 2020).

## Strategies and treatments to maintain a parental role and to function as “good mother”

Despite the medical complications of a cancer diagnosis during pregnancy it is important to provide women with cancer in pregnancy with the best possible positive experience of pregnancy and maternity period. Following the principles of ‘Mother-friendly care’ as close as possible within the knowledge that these pregnancies are considered to be high-risk pregnancies.

Women with cancer during pregnancy want to be treated as any other pregnant woman when it comes to maternity care. It is important for every health care professional to assess what the woman’s aspirations for this pregnancy are, how she wants to deliver, etc.

Health care professionals should be aware that many of the pregnant cancer patients are already mothers. A Canadian study in 2015 investigated how young mothers managed their maternal roles during their journey as patients with cancer (Strickland, J. T. et al., 2015). Four strategies that mothers implement to protect their children from psychological harm were identified: customizing exposure, reducing disruption to family life, finding new ways to be close, and increasing vigilance. ‘Safeguarding the Children’ is the explanatory model generated comprising these four strategies. Health care professionals can use this model to understand how best to meet the maternal concerns of young mothers during their cancer journey.

Ten steps of mother-friendly care (Lothian JA., 2007).

1. Offers all birthing mothers:
  - unrestricted access to the birth companions of her choice, including fathers, partners, children, family members, and friends;
  - unrestricted access to continuous emotional and physical support from a skilled woman—for example, a doula or labor-support professional; and
  - access to professional midwifery care.
2. Provides accurate, descriptive, and statistical information to the public about its practices and procedures for birth care, including measures of interventions and outcomes.
3. Provides culturally competent care—that is, care that is sensitive and responsive to the specific beliefs, values, and customs of the mother's ethnicity and religion.
4. Provides the birthing woman with the freedom to walk, move about, and assume the positions of her choice during labour and birth (unless restriction is specifically required to correct a complication) and discourages the use of the lithotomy position.
5. Has clearly defined policies and procedures for:
  - collaborating and consulting throughout the perinatal period with other maternity services, including communicating with the original caregiver when transfer from one birth site to another is necessary and
  - linking the mother and baby to appropriate community resources, including prenatal and post discharge follow-up and breastfeeding support.
6. Does not routinely employ practices and procedures that are unsupported by scientific evidence, including but not limited to the following:
  - shaving,
  - enemas,
  - intravenous drips,
  - withholding nourishment,

- early rupture of membranes, and
- electronic fetal monitoring.

Other interventions are limited, as follows:

- has an induction rate of 10% or less;
  - has an episiotomy rate of 20% or less, with a goal of 5% or less;
  - has a total cesarean rate of 10% or less in community hospitals and 15% or less in tertiary care hospitals; and
  - has a vaginal birth after cesarean rate of 60% or more, with a goal of 75% or more.
7. Educates staff in nondrug methods of pain relief and does not promote the use of analgesic or anesthetic drugs not specifically required to correct a complication.
  8. Encourages all mothers and families, including those with sick or premature newborns or infants who have congenital problems, to touch, hold, breastfeed, and care for their babies to the extent compatible with their conditions.
  9. Discourages nonreligious circumcision of the newborn.
  10. Strives to achieve the WHO/UNICEF *Ten Steps of the Baby-Friendly Hospital Initiative* to promote successful breastfeeding.

### *Early detection of symptoms of depression*

## Strategies and treatments for promoting mother-baby bonding

Distress during pregnancy is known to affect the mother-baby bonding and has an important impact on child development and maternal identity. Stress-relieving techniques such as relaxation can be offered to reduce stress levels and anxiety.

Health care professionals should be aware of the possibility that the attention on the disease process might override bonding with the baby. Side-effects of the treatment such as nausea, tiredness but also stress and anxiety about their own health might impede the mother-baby bonding. If possible, appointments for chemotherapy administration could be combined with obstetrical follow up. In this way focussing on the well-being of the child by regular ultrasound scans to assess growth and the regular palpation of the abdomen can reassure the mother. Also, in the postpartum period, regular visits to the paediatrician or follow up can reassure the mother about the child's development and health.

A high-risk pregnancy such as cancer during pregnancy does not prevent the implementation of 'Baby-friendly Hospital Initiatives'. Although breastfeeding is often not possible due to cytotoxic treatment or breast surgery, alternatives such as donor milk (depending on local facilities) should be offered.

Skin-to-skin care, also known as kangaroo-care should be promoted as much as possible because of its proven benefits for mother and baby, improving parental attachment and reducing the risk of a postpartum depression.

Rooming-in should be provided as much as possible. It means that mother and baby stay together 24 hours a day. When the baby needs to be admitted to a NICU ward it is important that the mother can visit her child as often as she wants without limitations. Rooming-in also improves the mother-baby bonding and reduces the risk of postpartum depression and facilitates skin-to-skin care. Also, when treatment is ongoing during the postpartum period, rooming-in should be enabled in the oncology ward.

#### Ten steps of Baby-friendly care (WHO and UNICEF, 1991)

- 1b.** Have a written infant feeding policy that is routinely communicated to staff and parents.
- 1c.** Establish ongoing monitoring and data-management systems.
- 2.** Ensure that staff have sufficient knowledge, competence and skills to support breastfeeding.
- 3.** Discuss the importance and management of breastfeeding with pregnant women and their families.
- 4.** Facilitate immediate and uninterrupted skin-to-skin contact and support mothers to initiate breastfeeding as soon as possible after birth.
- 5.** Support mothers to initiate and maintain breastfeeding and manage common difficulties.
- 6.** Do not provide breastfed newborns any food or fluids other than breast milk, unless medically indicated.
- 7.** Enable mothers and their infants to remain together and to practise rooming-in 24 hours a day.
- 8.** Support mothers to recognize and respond to their infants' cues for feeding.
- 9.** Counsel mothers on the use and risks of feeding bottles, teats and pacifiers.
- 10.** Coordinate discharge so that parents and their infants have timely access to ongoing support and care.

#### **Dilemma**

Counselling pregnant women diagnosed with cancer poses challenges and ethical dilemmas, particularly when women's best interest clashes with the unborn babies and the conceptions of the health professionals caring for them, i.e. women's human's rights vs legal status of the unborn foetus. Deciding which lives prevails over which, and making women active participants of the decisions pertaining their own health, seem to be affected by cultural and religious constructions, being a reflection of how each country/region respects human rights in general, and patient's autonomy and self-determination in particular.

Peter notes on this?

Future Perspectives: 'guidelines' for health care professionals working in the field of cancer in pregnancy

Conclusion

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