RESILIENCE AND FEAR OF RECURRENCE IN BREAST CANCER PATIENTS

Crumpei Irina PhD Fellow, SOP HRD/159/1.5/S/133675 Project, Romanian Academy Iasi Branch

Abstract: Breast cancer is the most common malignancy in women. At the same time it has one of the best survival rates among other types of cancer. Quality of life becomes an essential issue for breast cancer survivors. Fear of cancer recurrence is reported to be one of their most frequent worries. Unfortunately it often stays unaddressed. Fear of recurrence is associated to lower quality of life and functioning and to higher distress, anxiety, depression and morbidity. However, further studies should clarify the direction of causality. In spite of its important implications and its popularity among researchers, the fear of cancer recurrence doesn't have a reliable theoretical framework, validated measures or established predictors. Only few studies assess interventions addressing this problem. The purpose of this paper is to synthesise some of the results uncovering the reasons for the discrepancy between the concept's importance and popularity and the superficial, contradictory results. Implications for future research are discussed.

Keywords: breast cancer, fear of recurrence, quality of life, resilience

Introduction

Medical progress led to a longer term survivorship among cancer patients. Psychological studies shifted their interest to variables predicting quality of life. Fear of cancer recurrence is one of the most frequent worries of oncology patients in post-treatment phase. Between 50 and 75% of patients are anxious that the cancer might return (Baker et al, 2005). In spite of its prevalence, fear of recurrence is also among the most ignored issues cancer survivors have to face (Armes at al, 2009). Up to 40% of patients report the need for help to control their fear. Defined as the fear that the cancer will return or progress in the same organ or in another part of the body (Vickberg, 2001), fear of recurrence is persistent in time. Even 5 years after treatment more than two thirds of breast cancer patients report significant worry (Mast,1998).

Fear of recurrence shows strong associations to psychological distress (Hodges & Humphris, 2009) and has an important negative impact on quality of life. Simard & Savard (2009) studied the connection between fear of recurrence and dimensions of quality of life and found negative associations with most of them. Physical, professional, personal, social and cognitive well being are lower in women who fear the return of cancer.

In spite of its important implications and its popularity among researchers, the fear of cancer recurrence doesn't have a reliable theoretical framework, validated measures or established predictors. Only few studies assess interventions addressing this problem. The purpose of this paper is to synthesise some of the results uncovering the reasons for the discrepancy between the concept's importance and popularity and the superficial, contradictory results.

Predictors of fear of recurrence in breast cancer patients

Psychological variables

Fear of recurrence is a universal, justified reaction experienced by cancer survivors. However, there are various degrees of fear associated to corresponding levels of life impairment. Intervention efforts need consistent information about predictors and their mediators to efficiently structure healing therapies.

There are structural characteristics that predispose the patients to higher levels of worry and fear. Trait anxiety, negative affect and neuroticism represent a vulnerable background where fear of recurrence can easily emerge (Lee-Jones et al., 1997). Fear of cancer recurrence is not an irrational belief. Cancer survivors have to face the uncertainty of their post-treatment evolution described by vague statistics associated to their diagnosis. Therefore, higher tolerance to uncertainty can become a protective factor, helping patients to better cope with the risky unknown of their future. Almost half of women assessed after breast cancer treatment wonder if there are still cancerous cells in their bodies, reporting uncertainty (Wong & Bramwell, 1992). These worries are naturally accompanied by fear that the cancer might return. Besides, many authors studied uncertainty about cancer recurrence and described it in terms very similar to the concept of fear of recurrence (Mast, 1998; Gil et al., 2004).

Coping strategies are also related to fear of recurrence. Planful problem solving, positive reappraisal, self-control, acceptance of responsibility, avoidance and seeking social support are all connected to fear of recurrence (Hilton, 1988). Avoidance along with intrusive symptoms, arousal and distress are also traumatic reactions triggered by the trauma of cancer diagnosis. Avoidance helps lowering psychological distress in the first few months after diagnosis. However, on a longer term, it predicts higher levels of fear of recurrence (Simard & Savard, 2009; Stanton et al., 2002). Studies linking posttraumatic stress disorder to cancer diagnosis and fear of recurrence are still controversial reporting conflicting conclusions (Hampton & Frombach, 2000; Palmer et al., 2004; Black & White, 2005). On one hand, intrusive thoughts and higher cancer related vigilance are considered normal and beneficial for early detection of possible recurrences (Palmer et al., 2004). Moreover, women with breast cancer fail to meet all the criteria for PTSD diagnosis (Hampton & Frombach, 2000; Palmer et al., 2004). On the other hand, some studies report that cancer patients with higher levels of fear also show traumatic symptoms (Black & White, 2005). The intrusive thoughts about cancer return or progress are described as weak or moderate anxious ruminations (Simard, Savard & Ivers, 2010).

Demographic variables

There are still controversies regarding some of the demographic variables linked to the fear of recurrence. However younger age is consistently associated to higher fear across studies (Mast, 1998; Stanton et al., 2002). The vulnerable group seems to be between 18 and 45 years old. Post-menopausal women worry less about recurrence regardless of their age (Corter et al. 2012). McVea, Minier & Palensky (2001) assessed the relationship between income and fear of recurrence and found a negative correlation. On the other hand, there is no

consensus regarding the link between fear and education level. There are studies to report higher levels of fear in both less and better educated women (Vickberg, 2003; Mehnert et al., 2009). Simard et al. (2013) report in their systematic review four studies describing higher concern in women than men and twelve studies that found no relationship.

Clinical variables

Clinical variables such as stage of cancer, type of treatment, time since diagnosis etc, are stronger associated to actual risk of recurrence. However they show weaker and more controversial associations to patients' fear of recurrence. This contradiction shows the subjective nature of fear. Even if it is not an irrational belief and vigilance is a positive protective attitude for cancer patients, patients fear recurrence for the wrong reasons. They lack important information about risk factors and base their fear on misconceptions.

The type of intervention is one of the most studied clinical predictors of both recurrence and fear of recurrence. Objectively there is a slight higher risk of recurrence in patients who underwent conservatory intervention. Compared to mastectomy, the intervention only eliminates the affected area and conserves the breast. Hall & Fallowfield, (1989) report a higher fear of recurrence in women with conservatory intervention. Schover et al. (1995) found that mastectomy is associated to higher fear. Other studies found no connection between the type of intervention and fear of recurrence (Simard et al, 2013).

There is no consensus regarding associations between time since diagnosis and fear of recurrence either. While some authors consider that fear decreases with time (O'Neil, 1975), other state that it raises (Lampic, 1994) and others found no relationship between time and fear of recurrence (Sneeuw et al., 1992). Stein et al (2010) describe a more complex analysis of the association between time and fear. Examining a sample of nearly 10000 cancer patients he found that 60% of people in their first year since diagnosis experience clinical levels of fear. After 11 years, fear of recurrence is lower but still reaches the clinical threshold for one third of survivors. Between 6 and 11 years, Stein et al (2010) report stable levels of fear of recurrence. Kiebert et al. (1993) takes a different perspective on the temporal variations of the fear of recurrence stating that it gets higher before doctor visits and decreases two weeks after the visit.

Patients chose adjuvant chemotherapy to decrease the risk of recurrence and increase their survival rate. However, they report higher fear of recurrence compared to women who didn't opt for chemotherapy. The relationship is not better explained by the stage of cancer at diagnosis (Little & Sayers, 2004). Simard et al (2013) summarize similar conclusions in their review. They found 11 studies reporting a positive association between fear of recurrence and illness severity and 16 studies that did not find a relationship.

These results show the importance of correct information among women with breast cancer. Fear can be adaptive when it helps entertain a healthy life style with regular checkups and a deeper sense of meaning. However, when fear is based on misconceptions its purpose is compromised.

The role of fear of recurrence in cancer resilience

Weisman (1976) identifies an obstacle in studying resilience in cancer patients. If resilience is a trait people will vary even before cancer diagnosis depends on it. Resilient patients should be less fearful. However, resilience also depends on the psycho-social context in which the individual lives.

Cancer survivors have to deal with problems related to emotional difficulties, self-image, self-esteem, couple intimacy and sexuality, financial problems, pain and physical symptoms, social and professional difficulties (Vickberg, 2001). Lower levels of fear allow patients to focus on other activities and life events, returning to a normal functioning (Vickberg, 2001).

Simard et al (2013) counted in their review ten studies supporting the negative association between fear of recurrence and quality of life or well being. While some studies show contradicting results about the domains of functioning affected by the fear of recurrence, there is strong agreement about the relation to global quality of life and to unmet needs. The authors also report moderate evidence for the impact fear of recurrence has on quality of life. Better mental and emotional functioning was predicted by lower levels of fear. On the other hand, there are also multiple studies showing that fear of recurrence does not predict quality of life or physical functioning in cancer. These results suggest that even if there is strong, consistent support for the association between fear of cancer recurrence and patients' quality of life, causality is not yet fully understood. The direction of the relationship between the two variables needs further research.

Interventions for breast cancer survivors with fear of recurrence

In spite its important prevalence, fear of recurrence stays one of the most reported unmet needs of cancer survivors (Armes et al., 2009). This is explained by the lack of psychological intervention protocols designed to target this specific issue (Ozakinci, Sobota, Humphris, 2014). There is a lack of consensus among professionals who report a strong need for training in techniques to help people with fear of recurrence (Thewes et al., 2014). Thewes et al. (2014) show through their study that health professionals lack the ability to recognise fear of recurrence in their patients. Their estimations of patients' need for help are less than half of what patients themselves report. Training about help techniques should be accompanied with information about recognising and assessing fear of recurrence.

There is great variability in approaches used to manage concerns about recurrence. Psychologists and health professionals each base their techniques on their initial training and orientation. They don't have specific strategies developed for this particular issue (Thewes et al., 2014). Meditation, solution focused therapy, cognitive behavioural techniques, psycho-education, mindfulness, are all reported as techniques meant to lower fear of recurrence.

Van den Berg et al. (2012) describe an online self-management intervention for breast cancer survivors. They called it Breath, the breast cancer e-health intervention. Techniques used derive from cognitive behavioural therapies and from the self regulation model (Leventhal, 2005). Patients are invited to go through four domains during four month, spending around one hour per week. Looking back, emotional processing, strengthening and looking ahead are the four areas completing the intervention. The program has no therapist

supervision. Even if fear of recurrence is not the primary focus, assignments and tasks will refer to this particular issue as well.

Ozakinci, Sobota and Humphris (2014) describe in their paper two other interventions designed specifically for lowering fear of recurrence (Butow et al., 2013; Humphris, 2012). "Conquer Fear" (Butow et al, 2014) is an intervention that reunites elements from meta-cognitive therapy and acceptance and commitment therapy planned to take place during ten weeks in five sessions with a trained therapist. Authors also describe the AFTER program designed for head and neck cancer patients by Humphris (2012). The intervention uses strategies for the adjustment to the fear, threat or expectation of recurrence. It takes place through short telephone counselling.

Cognitive behaviour therapy offers specific alternatives for survivors of cancer with anxious preoccupation. Relaxation, activity scheduling, planning for the future, reality texting, decatastrophizing (Moorey & Greer, 2002).

Conclusions

Fear of recurrence is among the most frequently reported concerns in cancer survivors. The concept has been studied for decades. However there are still multiple deficiencies in addressing this issue. Risk factors are not yet fully understood. While younger age and female gender seem to be consistently associated to higher fear of recurrence, most of the others associated variables gather controversial results. Even clinical objective factors such as stage of disease, type of intervention or time since diagnosis are not always linked to fear of recurrence. If researchers cannot agree about associated factors, establishing causality and defining predictors is even more difficult. Even the impact on quality of life and wellbeing has great variability across studies.

Assessment of fear of cancer recurrence is another concern. There is still no agreement on what constitutes the clinical threshold. There is an objective risk of cancer return in most types of cancer and higher vigilance is advisable. The line between normal vigilance and clinical fear is not yet well defined. Intervention protocols are also scarce. Fear of recurrence is one of the most frequent unmet needs of cancer survivors.

ACKNOWLEDGEMENT: This paper is supported by the Sectoral Operational Programme Human Resources Development (SOP HRD), financed from the European Social Fund and by the Romanian Government under the contract number POSDRU/159/1.5/S/133675

BIBLIOGRAPHY :

Armes J, Crowe M, Colbourne L, et al. (2009) Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J Clin Oncol;27(36):6172–9.

Baker F, Denniston M, Smith T, West MM (2005) Adult cancer survivors: how are they faring? Cancer 104(11):2565–76

Black, E., K., White, C., A. (2005). Fear of recurrence, sense of coherence and posttraumatic stress disorder in haematological cancer survivors. Psycho-Oncology, 14: 510-515.

Butow PN, Bell ML, Smith AB, et al. Conquer fear: protocol of a randomised controlled trial of a psychological intervention to reduce fear of cancer recurrence. BMC Cancer. 2013;13(1):201

Corter AL, Findlay M, Broom R, et al. Beliefs about medicine and illness are associated with fear of cancer recurrence in women taking adjuvant endocrine therapy for breast cancer. Br J Health Psychol. 2013;18(1):168–81.

Gil, K., Mishel, M. H., Belyea, M., Germino, B., Porter, L., LeNey, I., & Stewart, J. (2004). Triggers of uncertainty about recurrence and long-term treatment side effects in older African and Caucasian breast cancer survivors. Oncology Nursing Forum, 31(3), 633-639.

Hall A, Fallowfield L (1989) Psychological outcome of treatment for early breast cancer: a review. Stress Med 5:167–75

Hampton, M. R., & Frombach, I. (2000). Women's experience of traumatic stress in cancer treatment. Health Care for Women International, 21.

Hilton, A. (1988). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. Journal of Behavioral Medicine, 12(1), 39-54.

Hodges LJ, Humphris GM. (2009) Fear of recurrence and psychological distress in head and neck cancer patients and their carers. Psychooncology;18(8):841–8.

Humphris G, Ozakinci G, Philp J, et al. (2012) The development, implementation, dissemination of a psychological intervention for patients with recurrent fears: the AFTER intervention. Protocol NHS Fife Research and Development Innovation Grant. Queen Margaret's Hospital Dunfermline Fife, UK: NHS Fife Research and Development.

Schover LR, Yetman RJ, Tuason LJ, et al (1995) Partial mastectomy and breast reconstruction. A comparison of their effects on psychosocial adjustment, body image, and sexuality. Cancer 75(1):54–64

Kiebert GM, Welvaart K, Kievit J (1993) Psychological effects of routine follow-up on cancer patients after surgery. Eur J Surg 159(11–12):601–7

Lampic C, Wennberg A, Schill JE, et al (1994) Anxiety and cancer-related worry of cancer patients at routine follow-up visits. Acta Oncol 33(2):119–25

Lee-Jones C, Humphris G, Dixon R, Hatcher MB (1997) Fear of cancer recurrence-a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. Psychooncology 6(2):95–105

Leventhal H, Halm E, Horowitz C, et al. Living with chronic illness: A contextualized, self-regulation approach. In: Sutton S, Johnston M, Baum A, editors. The Sage Handbook of Health Psychology: Sage Publications; 2005. p. 197–240.

Little, M., & Sayers, E. (2004). The skull beneath the skin: Cancer survival and awareness of death Psycho-oncology, 13, 190-198.

Mast ME (1998) Survivors of breast cancer: illness uncertainty, positive reappraisal, and emotional distress. Oncol Nurs Forum 25(3):555–62.

McVea, K. L. S. P., Minier, W. C., & Johnson Palensky, J. E. (2001). Low-income women with early stage breast cancer: Physician and Patient decision making styles. Psycho-Oncology, 10(2), 137-146.

Mehnert, A., Berg, P., Henrich, G., & Herschbach, P. (2009). Fear of cancer progression

and cancer-related intrusive cognitions in breast cancer survivors. Psycho-Oncology, 1481-1489.
Moorey, S. & Greer, S. (2002) Cognitive behaviour therapy for people with cancer, Oxford University Press: New York.
O'Neil MP (1975) Psychological aspects of cancer recovery. Cancer (July):271–3
Ozakinci, G., Sobota, A., Humphris, G. (2014) Fear of Cancer Recurrence Among Breast Cancer Survivors, Curr Breast Cancer Rep, 6:219–225.
Palmer, S., Kagee, A., Coyne, J., & DeMichele, A. (2004). Experience of trauma, distress and posttraumatic stress disorder among breast cancer patients. Psychosomatic Medicine, 66, 258-264.
Simard S, Savard J (2009) Fear of Cancer Recurrence Inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. Support Care Cancer 17(3):241–51
Simard, S., Savard, J., & Ivers, H. (2010). Fear of cancer recurrence:specific profiles and nature of intrusive thoughts. Journal of Cancer Survivorship, 4, 361-371.
Simard S, Thewes B, Humphris G, et al. (2013) Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. J Cancer Survivorship. 7(3):300–22.
Sneeuw KC, Aaronson NK, Yarnold JR, et al (1992) Cosmetic and functional outcomes of breast conserving treatment for early stage breast cancer. Relationship with psychosocial functioning. Radiother Oncol 25(3):160–6
Stanton AL, Danoff-Burg S, Huggins ME (2002) The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. Psychooncology 11(2):93–102
Stein K, Chiewkwei K, Spillers R editors (2010). Prevalence and correlates of fear of cancer recurrence among cancer survivors: results of the American Cancer Society's studies of cancer survivors (SCS). IPOS: Hope, Meaning & Science for quality of care in psycho-oncology and palliative care; 2010; Québec, 25–29 May. Psycho-Oncology
Thewes, B., Brebach, R., Dzidowska, M., Rhodes, P., Sharpe, L., Butow, P (2014) Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals. Psycho-Oncology 23: 390-396.
van den Berg SW, Gielissen MF, Ottevanger PB, et al. Rationale ofthe BREAst cancer ehealTH [BREATH] multicentre randomised controlled trial: an internet-based self-management intervention to foster adjustment after curative breast cancer by decreasing distress and increasing empowerment. BMC Cancer. 2012;12:394. This is an example of intervention that will examine fear of cancer recurrence as a secondary outcome.
Vickberg SM (2001) Fears about cancer recurrence: interviews with diverse sample. Cancer Practice 9:237–43
Vickberg, S. (2003). The concerns about recurrence scale (CARS): A systematic measure of woman's fears about the possibility of breast cancer recurrence. Annals of Behavioral Medicine, 25(1), 16-24.
Weisman, A. D. (1976). Early diagnosis of vulnerability in cancer patients. The American Journal of the Medical Sciences, 271(2), 187-196.
Wong CA, Bramwell L (1992) Uncertainty and anxiety after mastectomy for breast cancer. Cancer Nurs 15(5):363–71