Stress and Coping Mechanisms Among Breast Cancer Patients and Family Caregivers: A Review of Literature

*K.P. Mukwato, P. Mweemba, M.K. Makukula, M.M Makoleka

University of Zambia, School of Medicine Department of Nursing Sciences

ABSTRACT

Background: Breast cancer is the most common malignancy of women worldwide accounting for 23% of all newly diagnosed cancer cases. It is also the leading cause of cancer mortality, representing 14.1%. In Zambia, it is second to cervical cancer and its incidence is steadily increasing. A diagnosis of cancer regardless of stage is a stressful event impacting on all facets of the patient's life and that of her family caregivers. To minimize the impact, adaptive coping mechanisms are required.

Aim of the review: The aim of the review was to gain an in-depth understanding of the stress and coping mechanisms used by breast cancer patients and family caregivers.

Materials and methods: A comprehensive review of publications for the period 1980-2010 cited on Pub Med, Hinari, British National Index, African Journal Online was undertaken. Search terms included "stress", "coping", "breast cancer", "coping mechanisms", "coping mechanisms by breast cancer patients and family care givers".

Search Results: Of the 22 articles reviewed, 13 focused on coping with breast cancer, 5 on stress and adaptation to cancer and the last 4 on experiences of family members on care of the terminally ill. Eighteen of the 22 used solely qualitative

Katowa Patricia Mukwato University of Zambia School of Medicine Department of Nursing Sciences Email: <u>patricia.mukwato@unza.zm</u> or <u>mukwatop@yahoo.com</u> methodology while 4 used mixed methods. Analysis of the articles revealed 4 predominant coping mechanisms for both the patient and family: (a) seeking social support, (b) reliance on God, (c) positive suggestion/attitude or re-affirmation and (d) acquisition of information and education.

Conclusions: A diagnosis of breast cancer is a stressor to both the patient and the family caregivers. Coping mechanisms/strategies are therefore required in order to adapt.

BACKGROUND

Breast cancer is the most common malignancy of women worldwide accounting for 23% of all newly diagnosed cancer cases. It is also the leading cause of cancer mortality, representing 14.1%. In Zambia, it is second to cervical cancer and its incidence is steadily increasing^{1,2,3}. A diagnosis of breast cancer regardless of the stage can be stressful, impacting on multiple spheres of life, disrupting physical status, emotional and spiritual well-being and personal relationships for the patient and family. For patients diagnosed in the early stages, they experience the stress of coming to terms with the diagnosis, the experience of complex and usually long treatments, and the side effects of the different treatment modalities. For those diagnosed in the late stages, they too have to come to terms with their diagnosis, the fact that they will have to receive palliative as opposed to curative care and the fears and uncertainty about end of life^{5,6,7}.

^{*} Corresponding Author

Key words: Breast cancer, Stress, Coping, Patient and Family caregivers.

For the family, a cancer diagnosis for a family member creates multiple challenges, including physical demand for practical care giving, emotional strain, change in role and responsibilities, and adjustment to work and career schedules. In order to adapt/cope, both the patient and family caregivers ought to employ certain coping mechanisms. Individuals with terminal illness who utilize coping strategies have better quality of life compared to those who do not⁵.

AIM OF THE REVIEW

The aim of the review was to gain an in-depth understanding of the stress and coping mechanisms used by breast cancer patients and their family care givers.

MATERIALS AND METHODS

Data sources and search methods

The Following databases, Pub Med, Hinari, British National Index and African Journal Online were searched for the period 1980-2010. The search strategy involved hand-searching of current journals for health research, chronic care, oncology nursing and palliative care. Cited references from the journals were identified and retrieved. Search terms included "stress", "coping", "breast cancer", "coping mechanisms", and "coping mechanisms by breast cancer patients and family caregivers". Recurring topics were structured to focus the review; coping with breast cancer, coping with cancer diseases, impact of terminal illness, caring for the terminally ill, palliative care, family caregivers.

RESULTS

Of the 22 articles reviewed, 13 focused on coping with breast cancer, 5 on stress and adaptation to cancer and the last 4 on experiences of family members on care of the terminally ill. Eighteen of the 22 used solely qualitative methodology while 4 used mixed methods. Analysis of the 22 studies revealed that several researchers investigating how individuals cope with stressful situations have used Lazarus and Folkman's Transaction Model of Stress and Coping^{9,10,11,12,13,14,15}. Further analysis, revealed 4 predominant coping strategies by patients and family caregivers: (a) seeking social support, (b) reliance on God, (c) positive suggestion/attitude or re-affirmation (d) acquisition of information and education.

DISCUSSION

Stress and Coping Mechanisms Defined

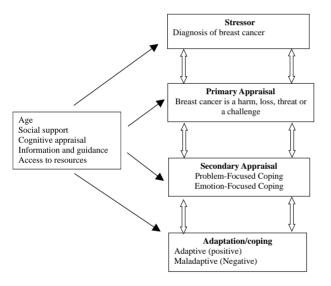
Lazarus and Folkman⁸, proposed one of the most comprehensive models of stress and coping known as the Transaction Model of Stress and Coping. The Transaction Model is built on the assumption that stress is a person-situation interaction, one that is dependent on the subjective cognitive judgment that arises from the interplay between the person and the environment. Any individual faced with either physical or psychological situation or event performs what is known as primary appraisal. Primary appraisal is an evaluation of an event for its personal meaning. If primary appraisal results in the person identifying the event or circumstance as a harm, loss, threat or a challenge, then the person experiences stress, if not then the event is benign. If stress is present, a person performs a secondary appraisal which focuses on possible coping strategies. There are two forms of coping strategies; Problem focused and emotional-focused coping^{8,10,17}

Problem-focused coping attempts to find solutions to resolve the problem causing the stress. Problem-focused coping strategies functions to alter the stressor by direct action, used when conditions are appraised as amenable. Strategies include learning new skills or developing new standards of behavior. Emotion-focused coping involves managing the emotions that an individual feels when a stressful event occurs. Emotional focused coping mostly occurs when an appraisal has been made that nothing can be done to modify the stressor. Emotion-focused strategies include wishful thinking, minimization, or avoidance^{8,10,17}.

Some strategies such as seeking social support serve both emotional and problem-focused functions ¹⁷. Neither of the two forms of coping is inherently adaptive or maladaptive, thus in stressful situations individuals may use a combination. The key to successful coping is the use of coping flexibility. Coping flexibility involves ability to change, and adapt coping strategies over time and across different stressful conditions as different strategies work effectively than others depending on circumstances $^{12,17.}$

Coping does not imply success,⁸ but efforts to resolve a stressful situation. Several factors influence the stress-coping response. Some factors are related to the stressor such as; intensity, scope, duration, number and nature of concurrent stressors and predictability. Those related to the individual experiencing the stressor include level of personal control, feeling of competence, availability of social support, information and guidance, and access to resources (equipment and supplies). Others are age at the time of stress and cognitive appraisal^{9,8}.

Figure 1: Diagram of conceptual framework of stress and coping with breast cancer.



Stress and Coping Mechanisms by Patients

Several studies have investigated the experiences and coping strategies of individuals diagnosed with breast cancer^{11,12,14, 18,19,20,22,23}. In a study conducted in Lebanon, by Doumit et al²¹ "Coping with breast cancer", the investigators identified social support and spirituality as important factors in coping. Participants described cancer as a 'cut in their lives that they had to deal with and the journey with cancer as continuous battle '. Participants spoke of facilitating and hindering factors to coping. Facilitating factors included reliance on God, positive support from work, family and husband, sharing with people who know (living the same experience) and considering cancer as any other disease in particular diabetes. Among the hindering factors, changed body image was prominent; all participants reported hair loss as having been detrimental to their coping. Being pitted by others was also stated as a hindering factor.

A positive relationship and full reliance on God gave participants hope that God was in control and that the disease was from him ²¹. The results suggest that belief in God helped the participants to accept the diagnosis and cope with the disease. Studies conducted in different parts of the world ^{22, 23 10} also reported that religion offers hope to those with cancer; it plays a major role in facilitating the disease acceptance process, and it has been found to have a positive effect on the quality of life of cancer patients. Such findings imply that the care given to cancer patients should have a spiritual component irrespective of an individual's religion. Individuals regardless of religion believe that God is powerful, capable and a source of inspiration and miracles²¹.

Similarly, Teleghani et al ²² reported that Iranian women with breast cancer used a religious approach for coping. They used strategies such as positive suggestion, hope, and intentional forgetfulness. Teleghani further stated that strategies such as relying on prayer, avoiding negative people, developing a positive attitude, having a will to live and receiving support from family, friends and support groups were used by patients. The benefits of prayer activities and experiences during difficult situations like dealing with cancer have been cited by other researchers ^{28, 29}. Meravigilia²⁹ stated that breast cancer survivors who reported high prayer scale scores had high psychological well-being despite having low education levels and less income to meet their needs. Other frequently used coping strategies are, positive cognitive restructuring, wishful thinking, making changes, engaging in physical activity, using medication and resting¹².

Culver et al¹⁹ in investigating coping and distress among women undergoing treatment of early stage breast cancer, reported four main coping responses: use of humour, religious coping, self-distraction and venting. The investigators compared the coping responses among women from three ethnic groups; non-Hispanic Whites, Hispanic and African Americans. Non-Hispanic Whites reported more use of humour, Hispanic women used more, venting and self-distraction while religious coping was the common strategy among African Americans.

The investigators further reported that religious coping was stable across time among African Americans and Hispanic but declined among the non-Hispanic whites after surgery. Although some ethnic differences were identified with regard to coping responses, findings point to a greater many similarities. Investigators concluded that distress was consistently related to avoidance coping strategies such as denial, self-distraction and venting. The decline in the use of religious coping noted among non-Hispanic Whites following surgery is contrary to Halstead et al ²³ who stated that length of survival did not result in different choices of strategies by his subjects.

In a qualitative meta-analysis conducted by Bertero and Chamberlain²⁰ a diagnosis of breast cancer made the women aware of the possibility of their own imminent death. They experienced an overwhelming feeling of fear; the only thing they could see was death. They described the feeling as "standing with one leg in the grave and the other on the edge" They lived in uncertainty. Two factors that reduced uncertainty were information and support from significant others. Information was cited as a very important factor in reducing uncertainty both practical and emotional. Practical support meant standing by the women's side to help her adjust to the new situation, while emotional support meant understanding the women's feelings of uncertainty and assuring them that significant others would offer constant comfort and love.

Stress and Coping Mechanisms by Family Caregivers

Family caregivers are stressed when a family member is terminally ill; hence they need information and education to cope ^{25, 26.} In a focus group discussion conducted by Kalnins²⁵, in a study entitled 'caring for the terminally ill: experiences of Latvian family care givers' a care giver voiced that they expected the family doctor to do the education and informative work. "Doctors have to explain to family caregivers what the patient's condition is because care givers look to them for medical care, education and validation of their care giving".²⁵.

When asked about any instructions for their role as caregiver, most subjects could not name any specific education or preparation; they learned practical patient care skills by trial and error ²⁶. Caregivers had no access to common patient care equipment or information. A daughter of a terminal cancer patient recalled the difficulties of caring '.....*we did it all ourselves, and I must say if you don't yell nobody will tell you anything*'. Such findings therefore, support caregivers' desire for several types of support from health care professionals, including emotional support, education in practical aspects of care and access to skilled guidance. It is assumed that care givers' burden is eased with access to education, resources and skilled guidance in palliative care. This situation requires changes in the education of health professionals for greater awareness of families' support needs.

Erickson and Lauri²⁷ indicated that families needed both information and emotional support to help them cope with their caring role. The study confirmed that emotional support from health professionals include conveying acceptance and responsiveness, listening to concerns, demonstrating understanding and showing concern for the family's welfare. Informational support needs for the family include information about cause and management of symptoms, how to care for the patient, likely prognosis, how to respond to sudden changes in patient's condition and available services in times of need. Such findings suggest a need for health care professionals to remain alert and respond to the family's needs for emotional and information support.

Despite several studies conducted on coping with breast cancer, literature search did not find any published study that has investigated coping mechanism on breast cancer in Zambia, other malignances or any chronic illness. However, there is literature on quality of life among Zambians with HIV and AIDS. Mweemba et al^{, 30} revealed that two thirds of the participants had good Spirituality, Religion and Personal Beliefs, (SRPB). The investigators concluded that SRPB and quality of life could be associated because of the importance of spiritual wellbeing in coping with chronic illness. Although the study was conducted on People living with HIV and AIDS, the implications of the finding on the association between SRPB and quality of life are important considering that breast cancer is a chronic condition if not diagnosed in the early treatable stages.

CONCLUSION

It is obvious that a diagnosis of breast cancer causes stress to both the patient and the family caregivers. Coping strategies employed could either be problem-focused or emotion-focused. Predominant coping strategies are; (a) seeking social support, (b) reliance on God, (c) positive suggestion/attitude or re-affirmation and (d) acquisition of information and education. The strategy employed influences adaptation to the diagnosis. Despite the demonstrated relationship between coping strategies and adaptation nothing is known about how Zambian breast cancer patients and their care givers cope and adapt. A study to explore the coping strategies used by patients with breast cancer and family care givers in Zambia is highly suggested. Further, a study on the association between coping strategies and adaptation is recommended. This will result in increased awareness about coping with breast cancer; consequently encourage the use of culturally sensitive coping strategies which will promote adaptive coping.

REFERENCES

- 1. Parkin, D.M., Bray, F., Ferlay, J. and Pisani, P. Global Cancer Statistics, 2002. *Cancer Journal of Clinicians* 2005; 55: 74-108.
- 2. World Health Organization. National Cancer Control Programmes: Policies and Guidelines, Geneva: WHO; 2002.
- Zambia Cancer Society. 2010. Cervical Cancer in Zambia. <u>http://www.zambiacncersociety</u> [accessed 19/04/10].
- 4. Carver, C. G. and Scheier, M. F. Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*. 1989; 56 (2) 267-183
- 5. Kearney, N. and Richardson, A. (2006). Nursing Patients with Cancer: Principles and Practice. Elsevier, London.
- 6. Guex, P. Introduction to Psycho-oncology. 1989. Routtledge, London.
- Lackey, N.R., Gates, M.F. ad Brown, G. African Americans Women's Experiences with the initial Discovery, Diagnosis and Treatment of Breast Cancer; *Oncol Nurs Forum*. 2001; 28:219-227.

- 8. Lazarus, R. S. and Folkman, S. Stress, Appraisal and Coping. New York: Springer; 1984.
- 9. Tung, H.H., Hunter, A. and Wei, J. Coping, Anxiety and Quality of life after coronary artery bypass graft surgery. *Journal of Advanced Nursing* 2008; 61 (6) 651-663.
- Livneh H. Psychological adaptation to cancer: the role of coping strategies. *J Rehabil.* 2000; 66(2):40-49
- 11. Li, J. and Lambert, V.A. Coping strategies and predictors of general wellbeing in women with breast cancer in the People's Republic of China. *Journal of Nurs Health Sci.* 2007; 9 (3) 199-204.
- 12. Manuel, J., Burwell, S., Crawford, S. et al. Young women' perception of coping with breast cancer. *Journal of Cancer Nursing* 2007; 30 (2): 85-94.
- 13. Mitchell, D. Stress, coping and appraisal in an HIV Sero-positive Rural Sample: 2004
- Hack, T.F. and Degner, L.F. Coping responses following breast cancer diagnosis predict psychological adjustment three years later. *Journal of Psychoncology* 2004; 13 (4): 235-247.
- 15. Zakowski, S., Hall, A., Klein, L. and Baum, A. Appraised control, coping and stress in a community Sample. A test of the goodness-of-fit hypothesis, *Annals of Behavioral Medicine* 2001; 23 (30) 158-165.
- Vitaliano, P., Russo, J, Carr, J. et al .The ways of coping Checklist. Revision and Psychometric properties. *Multivariate Behavioral Research* 1985; 20 2-36.
- Folkman, S, Lazarus, R.S., Dunkel-Scheter, C. et al. Dynamics of a stressful encounter: Cognitive appraisal, Coping and encounter outcomes. *Journal of Personality and Social Psychology* 1968; 50 992-1003.
- 18. Landmark, B.T., Bohler, A. Loberg, K and Wahl, A.K. Women with newly diagnosed breast cancer and their perceptions needs in a healthcare context. *Journal of Nur Health Care Chronic illn.* 2008; 17 (3): 192-200.
- 19. Culver, J.L., Arena, P.L., Antoni, M.H. and Carver, S.C. coiping and distress among women under treatment of early stage breast cancer: Comparing African Americans, Hispanic and

Non-Hispanic Whites. *Psycho-oncology 2002*; 11 495-505.

- Bertero, C. and Chmberlain, W. M. Breast cancer diagnosis and its treatment affecting self: A Meta-synthesis. *Journal of Cancer Nursing*. 2007; 30 (3) 194-201.
- Doumit, M. A. A., Huijer, H.A., Kelley, J. and Saghir, N. Coping with breast cancer: Phenomenological Study. *Journal Cancer Nursing* 2010;33 (2) 33-39.
- 22. Teleghani, F., Yekta, Z. and Nasrabadi, A. N. Coping with breast cancer in newly diagnosed Iranian women. *J Adv Nurs.* 2006; 54 (3): 265-272.
- 23. Halstead, M.T. and Fernsler, J.I. Coping strategies of long term cancer survivors. *International Journal of Cancer Care* 1994; 17 (2).
- 24. Weaver, A.J. and Flannelly, K.J. The role of religion/spirituality for cancer patients and their caregivers. *South Med J.* 2004; 97 (12):1210-1214.

- 25. Kalnins, I. Caring for the terminally ill: experiences of Latvian family caregivers. *International Nursing Review* 2006; 553, 19-135.
- 26. Seymour, J., Ingleton, C., Payne, S. and Beddow, V. Specialist palliative care: patients' experiences. *Journal of Advanced Nursing*. 2003; 44 (1) 24-33.
- 27. Erickson, E. and Lauri, S. Information and emotional support for cancer patient,s relatives. 2000; *Eur Journal of Cancer Care*. 4: 118-121.
- Gall, T. L. and Cornblat, M.W. Breast cancer survivors give voice. A Qualitative analysis of spiritual factors in long-term adjustment.2002. *Psycho-oncology*. 11:523-535.
- 29. Meravigilia, M. Effects of spirituality on Breast cancer survivors. 2007. *Oncology Nursing Forum.* 33 (1) E1-E7.
- 30. Mweemba, P. 2008. Quality of life among rural and urban Zambian men and women with HIVand AIDS. Personal communication.