

## Hope and Quality of Life in Caregivers of Cancer Patients

Geeta Sunkarapalli<sup>1\*</sup>, Apeksha Agarwal<sup>2</sup>, Swati Agarwal<sup>3</sup>

### ABSTRACT

Hope as conceptualized by Dufault and Martocchio (1985) "is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good." Quality of Life is defined by Lehto, Ojanen and Kellokumpu-Lehtinen (2005) "as appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal." The objective of this study was to determine the relationship between Hope, its dimensions and Quality of Life in Caregivers of Cancer Patients. A non-probability purposive sampling method was used to draw the sample of 40 Caregivers of patients with Breast and Ovarian Cancer belonging to lower middle class and upper lower class. The Herth Hope Index (HHI) (Herth, 1992) and the Caregiver Quality Of Life Index- Cancer (CQOLC) (Weitzner, Jacobsen, Wagner, Friedland & Cox, 1999) were administered. There was significant difference in the levels of Positive Readiness & Expectancy among caregivers based on their socio-economic status. Positive Readiness & Expectancy and Interconnectedness were found to be negatively correlated with quality of life. Results indicated no significant difference in the levels of Hope and Quality of Life based on age and type of cancer.

**Keywords:** Breast Cancer, Caregivers, Hope, Ovarian Cancer, Quality Of Life

Hope "is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (Dufault & Martocchio, 1985). Hope indicates an individual's motivation as well as their faith in their abilities to achieve personally significant goals and ambitions. It is a dynamic life force, which is supported by relationships, resources and work, learning and thinking, and results in the energy necessary to work for a desired future. Stotland (1969) stated that hope drives a person to move, act and achieve something and on the other hand its absence makes them dull and purposeless. Hope gives meaning to an individual's life and also brings happiness in people's lives (Holt, 2000). Besides having future oriented nature hope provides

<sup>1</sup> Assistant Professor, Dept of Psychology, St. Francis College for Women, Begumpet, Hyderabad, Telangana, India

<sup>2</sup> Student, Dept of Psychology, St. Francis College for Women, Begumpet, Hyderabad, Telangana, India

<sup>3</sup> Assistant Professor, Dept of Psychology, St. Francis College for Women, Begumpet, Hyderabad, Telangana, India

\*Responding Author

## **Hope and Quality of Life in Caregivers of Cancer Patients**

individuals strength to resolve their problems and face difficulties, such as losses, adversities, solitude and agony (Herth, 1992).

In the context of a cancer diagnosis, hope takes on a more specific nature in terms of the patient and their family being hopeful about treatment, cure, recovery and remission. Hope can enable individuals to look beyond their current pain, suffering, and turmoil. It is associated with well-being and quality of life and is one of the key components while coping with adversities. Loss of hope and a narrowing of expectations and goals for life are believed to reduce quality of life (Herth, 2000). For cancer patients hope is a vital component as it is considered an effective coping strategy, providing adaptive power to help them get through the difficult situation and achieve desired goals (Ebright & Lyon, 2002; Herth, 1989, 1990). Kavradim, Özer, and Bozcu, (2013) found that net family income, knowledge level about the ill health, feeling of improvement, realization of acceptable family support by the patient, feeling anxious or worried and presence of fear were independently related with hope. They concluded that physical, psychological well-being and financial, information and support needs are directly and independently related with hope in people with cancer.

Quality of Life is defined as “appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal.” It is a multifaceted construct incorporating perceptions of positive aspects of the dimension such as social, physical, cognitive and emotional functions, as well as the negative aspects of dimensions such as somatic discomfort and other symptoms produced by a disease or its treatment (Lehto, Ojanen & Kellokumpu-Lehtinen, 2005).

“*Family Caregiver* refers to a wide range of unpaid care provided in response to illness or functional impairment to a chronically ill or functionally impaired older family member, partner, friend, or neighbor that exceeds the support usually provided in family relationships” (Schumacher, Beck, & Marren, 2006). A family caregiver is a person who belongs to the patient’s family, who takes care and is responsible for the patient and who commits most of his or her time to this task without any economic retribution (Dwyer, Lee, & Jankowski, 1995). Caregivers belong to the patient’s informal support system and as such the patient is dependent on the caregiver to carry out most of his or her daily activities. They also play a critical role in providing guidance and aid to the patient.

It has been realised, that illnesses like cancer affect not only the patient, but the entire family as well. Families are a necessary source of care giving and support for the patient. Individuals of all ages are mostly dependent on the informal care provided by the patient’s relatives in carrying out most of the routine daily life activities. Research has shown the distress levels of caregivers to be high; however, very few studies have been done to show the broader impact of care giving on quality of life. Care giving responsibilities initiate competing demands that make caregivers vulnerable to physical diseases and psychological distress, which thereby hinders their social involvement (Covinsky, et. al. 1994; Donelan, et. al. 2002; Pitceathly & Maguire, 2003). The

## **Hope and Quality of Life in Caregivers of Cancer Patients**

combination of physical demands, anticipated loss and prolonged psychological distress of caregiving can seriously compromise caregiver's quality of life when they provide end-of-life care to a terminally ill cancer patient (Wolff, Dy, Frick & Kasper, 2007; Matthews, Baker & Spillers, 2004; Weitzner, McMillan, & Jacobsen, 1999; Sherman, Ye, McSherry, Calabrese, & Gatto, 2006).

The primary caregivers have to provide demanding care to severely ill patients for a varied period ranging from months to years. The increased responsibility and challenge of care provision may lead to negative as well as positive effects on primary caregiver's mental health and health-related quality of life (Andershed & Ternestedt, 1998; Hoffmann & Mitchell, 1998; Given et al., 1993). Grov, Dahl, Moum, & Fossa (2005) believed that limited research was done on the quality of life and mental health of primary caregivers to advanced cancer patients. Their study on primary caregivers of cancer patients examined the anxiety, depression, and quality of life levels in them and found that there was significantly higher level of anxiety in primary caregivers. Family caregivers may be psychologically and physically strong at the starting, but it becomes difficult and exhausting when the patient's death approaches.

Cancer is an overwhelming disease and has a strong influence on the caregiver's levels of hope. Stressful events such as pain, ill health, reoccurrence, severity, obligation and burden on the caregivers has an impact on caregiver's hope levels, which may in turn have a significant effect on caregiver's quality of life. Thus this study was initiated to measure the levels of hope, quality of life in caregivers of cancer patients and examining the relationship between the two variables in detail.

### ***Objectives***

1. To determine if there is a difference in the levels of Hope, its dimensions and Quality Of Life between Caregivers of Breast Cancer Patients and Ovarian Cancer Patients.
2. To determine if there is a difference in the levels of Hope, its dimensions and Quality Of Life between Caregivers of Breast Cancer Patients and Ovarian Cancer Patients of different age groups.
3. To determine if there is a difference in the levels of Hope, its dimensions and Quality Of Life between Caregivers of Breast Cancer Patients and Ovarian Cancer Patients belonging to Upper Lower Class and Lower Middle Class socio economic status.
4. To determine if there is a relation between the dimensions of Hope and Quality Of Life in caregivers of cancer patients.

## **METHOD**

### ***Plan and Design***

The present study is a quantitative study with a between groups design to examine the differences in the levels of hope and its dimensions and quality of life between caregivers of breast cancer and ovarian cancer patients. Caregivers of cancer patients of different socio

## **Hope and Quality of Life in Caregivers of Cancer Patients**

economic status and age were also compared to determine if age and socio economic status played a role in the dimension of hope and quality of life in the caregivers.

### ***Participants***

The sample was collected using non-probability purposive sampling method and included 40 caregivers - 20 breast cancer patients' caregivers and 20 ovarian cancer patients' caregivers. The caregivers participated voluntarily for the study and their informed consent was obtained before including them in the study. The sample was collected from two prominent cancer hospitals; MNJ Institute of Oncology and Bibi Cancer Hospital from the metropolitan city of Hyderabad. The inclusion criteria for the participants was that they had to be within the age group of 20-40 years, they had to be from upper lower class and lower middle socio economic class, they had to be the primary family caregivers of the cancer patients who had been undergoing chemotherapy for breast or ovarian cancer diagnosed in the last six months. Within this group the exclusion criteria was if the diagnosis of cancer had been made more than 6 months before, if the cancer patient had undergone surgery, or radiation therapy, and if there were any other family members who had a chronic illness or terminal illness.

### ***Instruments***

In addition to the personal information schedule two other standardized tools were used in the study, first the Herth Hope Index to measure Hope and the Caregiver Quality Of Life Index-Cancer to measure quality of life in the caregivers of cancer patients. The Herth Hope Index (HHI) developed by Herth (1992) is a 12-item instrument that is equally divided between three sub-scales which are: (a) temporality and future, (b) positive readiness and expectancy, (c) interconnectedness. For each item the participant responded to a four-point Likert format scale, which ranged from strongly disagree to strongly agree. Two items were reverse scored. The total score could range from 4 to 16 for each sub-scale with higher scores suggesting higher levels of hope. Convergent validity of HHI is indicated by the high correlations with the Herth Hope Scale ( $r = 0.92$ ), the Existential Well-Being Scale ( $r = 0.84$ ) and the Nowotny Hope Scale ( $r = 0.81$ ), and divergent validity is indicated by the negative relationship with the Hopelessness Scale ( $r = -0.73$ ). The reliability of HHI was high as the alpha coefficient was 0.97 and test-retest reliability after two weeks was 0.91.

Caregiver Quality Of Life Index-Cancer (CQOLC) was developed by Weitzner, Jacobsen, Wagner, Friedland, and Cox (1999) to assess Quality of Life in the caregivers of cancer patients and is a 35 item instrument with a five-point Likert-type scale, ranging from not at all to very much. Eight of the items were reverse scored and a high score on the scale suggests better Quality of Life. Test-retest reliability was 0.95 and internal consistency was 0.91 indicating the scale to be reliable.

## Hope and Quality of Life in Caregivers of Cancer Patients

### **Procedure**

The study was initiated after taking due permission from MNJ Institute of Oncology and Bibi Cancer Hospital. The participants were made comfortable, explained the purpose of the study and their informed consent was taken. Written and verbal instructions were given and they were encouraged to seek clarification in case of any doubts. The tools which were translated into the regional languages of Hindi and Telugu for the convenience and understanding of the participants were administered when required. Data collected was analysed using SPSS v 20 and appropriate statistical analyses were used in line with the objectives of the study.

## **RESULTS**

Mean, Standard Deviation, t-test, and Pearson's Product Moment Correlation were used to analyze the data. Table 1 shows the independent t test results of dimensions of hope and quality of life in the caregivers of breast cancer and ovarian cancer patients. Results show that there are no significant differences in the levels of Hope and Quality of Life between caregivers of breast cancer and ovarian cancer patients.

**Table 1 Mean, Standard Deviation (SD) and t ratio of temporality and future, positive readiness and expectancy, interconnectedness and quality of life in caregivers of breast cancer patients and ovarian cancer patients.**

Scale	Breast Cancer Caregivers		Ovarian Cancer Caregivers		t Value
	Mean	SD	Mean	SD	
Temporality and Future	12.35	2.18	12.05	1.90	0.46
Positive Readiness and Expectancy	13.30	2.00	13.10	1.97	0.32
Interconnectedness	13.70	1.95	12.75	2.57	1.32
Caregiver Quality Of Life	57.10	16.82	63.15	15.21	1.19

Table 2 shows the independent t test results of dimensions of hope and quality of life of the caregivers of breast cancer and ovarian cancer patients in different age groups. Results show that there are no significant differences in the levels of hope and quality of life between caregivers of cancer patients in the age group of 20- 30 and 30- 40 years indicating that age doesn't have an influence on hope and quality of life of caregivers.

## Hope and Quality of Life in Caregivers of Cancer Patients

**Table 2 Mean, Standard Deviation (SD) and t ratio of temporality and future, positive readiness and expectancy, interconnectedness and quality of life in caregivers between the age group 20-30 years and 30-40 years.**

Scale	20-30 Years		30-40 Years		t Value
	Mean	SD	Mean	SD	
Temporality and Future	12.05	2.06	12.35	2.03	0.46
Positive Readiness and Expectancy	13.25	1.97	13.15	2.01	0.16
Interconnectedness	13.10	2.47	13.35	2.18	0.33
Caregiver Quality Of Life	62.75	16.05	57.50	16.17	1.03

Independent t test results of dimensions of hope and quality of life of the caregivers of cancer patients belonging to different socio economic status are presented in table 3. Results show that there are no significant differences in the levels of two of the dimensions of hope - temporality and future and interconnectedness and quality of life indicating that socio economic status doesn't have an influence on these dimensions of hope and quality of life of caregivers. However, there was difference in the dimension of positive readiness and expectancy with caregivers from lower middle class showing higher levels than upper lower class.

**Table 3, Mean, Standard Deviation (SD) and t ratio of temporality and future, positive readiness and expectancy, interconnectedness and quality of life in caregivers between the Upper Lower Class and Lower Middle Class.**

Scale	Upper Lower Class		Lower Middle Class		t Value
	Mean	SD	Mean	SD	
Temporality and Future	11.95	2.23	12.60	1.90	0.00
Positive Readiness and Expectancy	12.55	1.96	13.90	1.77	2.29*
Interconnectedness	12.70	2.77	13.85	1.63	1.59
Caregiver Quality Of Life	59.15	14.97	61.70	17.26	0.49

Note: \*p < 0.05

Results of correlation analysis, presented in table 4, show that positive readiness and expectancy as well as interconnectedness were negatively related with caregivers' quality of life. Increase in

## **Hope and Quality of Life in Caregivers of Cancer Patients**

positive readiness and interconnectedness resulted in decrease in the quality of life of caregivers of cancer patients.

**Table 4, Correlation between Hope its dimensions namely temporality and future, positive readiness and expectancy, interconnectedness and Quality of Life.**

	<b>Temporality and Future</b>	<b>Positive Readiness and Expectancy</b>	<b>Interconnectedness</b>
Caregiver Quality Of Life	-0.15	-0.35*	-0.36*

*Note:*\*p < 0.05

## **DISCUSSION**

The purpose of this study was to determine if there is a difference in the levels of hope, its dimensions and quality of life in caregivers of cancer patients based on the type of cancer – breast and ovarian, age – 20 to 20 and 30 to 40 years; and socio economic status - upper lower and lower middle class. The results reveal that type of cancer and age did not play a role in the levels of hope and quality of life in caregivers of cancer patients. There was no significant difference in the levels of hope, its dimensions -temporality and future, interconnectedness and quality of life in the caregivers of different socio economic status as well. However, levels of positive readiness and expectancy differed significantly with caregivers from a higher socio economic status, that is, lower middle class reporting higher levels than those from upper lower class.

Research looking into factors affecting hope in caregivers has found that a number of factors play a role with both individual, social and disease related factors influencing hope. Type of cancer may directly not have any influence on hope in cancer patients and their caregivers. However, it may have indirect effects by way of influencing the treatment, effect of treatment, impact on the patient's self image and so on. Hope also appears to be dynamic and undergoes changes depending on the length of treatment, stage of treatment and type of treatment. In the present study, patients who had been recently diagnosed were recruited and all were undergoing chemotherapy and this could account for there being no differences in the levels of hope in the caregivers. Age was again found to have no direct influence on the levels of hope in the present study; though Lohne, Miaskowski and Rustoen (2012) found that younger caregivers were at risk of having lower levels of hope, their sample was considerably older than the sample of the present study.

In the present study socio economic status influences the dimension of hope - positive readiness and expectancy, positively in cancer caregivers. Research indicates that socio economic status has a positive impact on cancer survival and quality of life as it may increase access to resources- financial, tangible, informational and social (Artinyan et al., 2010; Clegg et al., 2009). Socio

## **Hope and Quality of Life in Caregivers of Cancer Patients**

economic status also has indirect effects as the lower middle class caregivers could be more educated as compared to the upper lower class caregivers and be more aware about the disease, suffering of the patient, the ongoing treatment and how to take care of the patient. Further they could be financially more stable as compared to the upper lower class caregivers. These could be some possible factors for the higher levels of positive readiness and expectancy level.

The present study enabled the measurement of hope and quality of life in a sample comprised of the family caregivers. The results revealed that there was significant negative correlation between positive readiness and expectancy, and quality of life, as well as between interconnectedness and quality of life. Hope and quality of life are related concepts as found in a study on hospice patients with cancer (Brown, 2005).

Despite the findings of the study, it has a few limitations. Firstly, this study consisted of a small sample and did not take a cross section sample of caregivers from across various socio-economic strata. The sample was also restricted with the age of the caregivers taken into consideration and the type of cancer as well. Thus future research in this area should fill these lacunae, by taking a wider sample with people from different socio economic strata, rural areas, ages, etc.

Caregivers of cancer patients undergo intense stress as they have the dual responsibility of taking care of the physical and psychological needs of the cancer patient as well as coping with their own distress arising from having a family member suffer with cancer. Factors such as stress, fear, anxiety, burden, depression, and hope can affect a caregiver's psychological well-being which in turn can affect their quality of life. Social support for the caregivers can have indirect effects on the patients' recovery as well. Therefore, various psychological counseling sessions should be administered by counselors to the patients as well as their caregiver to improve their quality of life.

### **Acknowledgments**

The author appreciates all those who participated in the study and helped to facilitate the research process.

### **Conflict of Interests**

The author declared no conflict of interests.

## **REFERENCES**

- Andershed B., & Ternestedt B. M. (1998). Involvement of relatives in the care of the dying in different care cultures: involvement in the dark or in the light? *Cancer Nursing*, 21, 106–116.
- Artinyan, A., Mailey, B., Sanchez-Luege, N., Khalili, J., Sun, C. L., Bhatia, S., ... & Kim, J. (2010). Race, ethnicity, and socioeconomic status influence the survival of patients with hepatocellular carcinoma in the United States. *Cancer*, 116(5), 1367-1377.

## **Hope and Quality of Life in Caregivers of Cancer Patients**

- Brown, C. (2005). *Hope and quality of life in hospice patients with cancer* (Doctoral dissertation, University of South Florida).
- Clegg, L. X., Reichman, M. E., Miller, B. A., Hankey, B. F., Singh, G. K., Lin, Y. D., ... & Bernstein, L. (2009). Impact of socioeconomic status on cancer incidence and stage at diagnosis: selected findings from the surveillance, epidemiology, and end results: National Longitudinal Mortality Study. *Cancer causes & control*, 20(4), 417-435.
- Covinsky, K. E., Goldman, L., Cook, E. F., Oye, R., Desbiens, N., Reding, D.,... & Cryer, H. G. (1994). The impact of serious illness on patients' families. *Jama*, 272(23), 1839-1844.
- Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P. H., Levine, C., & Gould, D. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs*, 21(4), 222-231.
- Dufault, K., & Martoccio, B. C. (1985). Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *The Nursing Clinics of North America*, 20(2), 379-391.
- Dwyer, J., Lee, G., & Jankowski, T. (1995). Reciprocity, elder satisfaction and caregiver stress and burden: The exchange of aid in the family caregiving relationship. *Journal of Marriage and Family*, 35-43.
- Ebright, P. R., & Lyon, B. (2002). Understanding hope and factors that enhance hope in women with breast cancer. *Oncology Nursing Forum*, 29, 561-568.
- Given, C. W, Stommel, M., Given, B., Osuch, J., Kurtz, M. E., & Kurtz, J. C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology*, 12, 277-285.
- Grov, E. K., Dahl, A. A., Moum, T., & Fosså, S. D. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16(7), 1185-1191.
- Herth, K. (1990). Fostering hope in terminally-ill people. *Journal of Advanced Nursing*, 15(11), 1250-1259.
- Herth, K. (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing*, 17(10), 1251-9.
- Herth, K. (2000). Enhancing hope in people with a first recurrence of cancer. *Journal of Advanced Nursing*, 32(6): 1431-41.
- Herth, K. A. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum*, 16(1), 67-72.
- Hoffmann, R. L., & Mitchell, A. M. (1998, October). Caregiver burden: historical development. In *Nursing Forum* (Vol. 33, No. 4, pp. 5-12). Blackwell Publishing Ltd.
- Holt, J. (2000). Exploration of the concept of hope in the Dominican Republic. *Journal of Advanced Nursing*, 32(5), 1116-1125.
- Kavradim, S. T., Özer, Z. C., & Bozduk, H. (2013). Hope in people with cancer: a multivariate analysis from Turkey. *Journal of advanced nursing*, 69(5), 1183-1196.

## **Hope and Quality of Life in Caregivers of Cancer Patients**

- Lehto, U. S., Ojanen, M., Kellokumpu-Lehtinen, P. (2005) Predictors of quality of life in newly diagnosed melanoma and breast cancer patients. *Annals of Oncology*, 16, 805-816
- Lohne, V., Miaskowski, C., & Rustøen, T. (2012). The relationship between hope and caregiver strain in family caregivers of patients with advanced cancer. *Cancer nursing*, 35(2), 99-105.
- Matthews, B. A., Baker, F., & Spillers, R. L. (2004). Family caregivers' quality of life: influence of health protective stance and emotional strain. *Psychology & Health*, 19(5), 625-641.
- McMillan, S. C. (1995). Quality of life of primary caregivers of hospice patients with cancer. *Cancer Practice*, 4(4), 191-198.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of cancer*, 39(11), 1517-1524.
- Schumacher, K., Beck, C. A., & Marren, J. M. (2006). Family Caregivers: caring for older adults, working with their families. *AJN The American Journal of Nursing*, 106(8), 40-49.
- Sherman, D. W., Ye, X. Y., McSherry, C., Calabrese, M., & Gatto, M. (2006). Quality of life of patients with advanced cancer and acquired immune deficiency syndrome and their family caregivers. *Journal of palliative medicine*, 9(4), 948-963.
- Stotland, E. (1969). *The psychology of hope*. San Francisco: Jossey-Bass.
- Weitzner, M. A., Jacobsen, P. B., Wagner Jr, H., Friedland, J., & Cox, C. (1999). The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8(1-2), 55-63.
- Wolff, J. L., Dy, S. M., Frick, K. D., & Kasper, J. D. (2007). End-of-life care: findings from a national survey of informal caregivers. *Archives of Internal Medicine*, 167(1), 40-46.

**How to cite this article:** G Sunkarapalli, A Agarwal, S Agarwal (2016), Hope and Quality of Life in Caregivers of Cancer Patients, International Journal of Indian Psychology, Volume 4, Issue 1, No. 69, ISSN:2348-5396 (e), ISSN:2349-3429 (p), DIP:18.01.006/20160401, ISBN:978-1-365-45447-9