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Hope in Caregivers of Heart, Cancer and AIDS Patients

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Abstract:
Heart, cancer and AIDS are very serious diseases rising in the world. These diseases not only create distress in the patient's life but also influence negatively caregivers' life. This distress thus, affects the hope of caregivers. Many studies have been carried out on the various aspects of heart, cancer and AIDS patients. However, few comparative researches have been done on hope of caregivers of these diseased groups. In the light of above stated context, the present research was planned and carried out with the objectives of measuring and comparing hope of caregivers of heart, cancer and AIDS patients. Total sample of the study comprised 120 subjects, 40 in each group i.e. caregivers of heart, cancer and AIDS patients. Data was collected from various hospitals of New Delhi. For measuring Hope, Trait Hope scale was used. ANOVA and Post-Hoc tests were used to analyze the data. Results showed a significant difference between caregivers of heart, cancer and AIDS patients on overall hope and agency and pathway dimensions of hope. Hope was also found to be higher in caregivers of Heart and cancer patients as compared to caregivers of AIDS patients.

Keywords: *Hope, caregivers, heart, cancer, AIDS patients*

1. Introduction

1.1. Caregiver

A caregiver has been broadly defined as someone who provides a broad range of financially uncompensated ongoing care to family members, friends or neighbors in need due to physical, cognitive, or mental health conditions (Canadian Caregiver Coalition, 2001). Patients depend on family caregivers for assistance with daily activities, managing complex care, navigating the health care system, and communicating with health care professionals. In other words, factors such as the physical and psychological demands made by care recipient, the limitation on freedom and social interactions that accompany the care recipient's need for supervision, the financial burden, and the additional roles assumed by the most carers including those of wife, parent, spouse and employee, all contribute to carer distress. This distress (physical, emotional and financial) may also increase caregiver vulnerability to injury and illness (Mitnick, Leffler & Hood, 2009).

Even with the variety of community services available today, family members are often the primary caregivers for people with a chronic illness (Smith, Greenberg, & Mallick Seltzer, 2007). Family caregiving, or "the informal (unpaid) care provided by family members that goes beyond customary and normative social support," is essential to the well-being of patients with serious illness (National Consensus Project, 2002). Family caregivers play a critical role in our health and long term care system by providing a significant proportion of the care for both the chronically ill and aging (American psychological Association, 2014). Boice (1998) describes chronic illness as living with a condition which drastically alters an individual's daily activities for more than three months out of the year, or requires hospitalization for the same time period. Some of the specific illnesses that fall within the category of a chronic illness include: sensory and nervous system disorders, lupus, diabetes, cystic fibrosis, cancer, multiple sclerosis, and cardiovascular disease (Boice, 1998).

Thus, Heart disease, cancer and AIDS among many others are the diseases which require caregivers:

1.2. Heart Disease

Cardiovascular disease (also called heart disease) is a class of diseases that involve the heart, the blood vessel (arteries, capillaries, and veins) or both (Maton, Jean, Charles, Susan, Maryanna, David & Jill, 1993).

According to World Heart Foundation (2014), common cardiovascular conditions are:

1.2.1. Rheumatic Heart Disease
Rheumatic heart disease is caused by one or more attacks of rheumatic fever, which then do damage to the heart, particularly the heart valves.

1.2.2. Hypertensive Heart Disease
High blood pressure of unknown origin (primary hypertension) or caused by (secondary hypertension) certain specific diseases or infections, such as tumor in the adrenal glands, damage to or disease of the kidneys or their blood vessels.

1.2.3. Ischemic Heart Disease
Heart ailments caused by narrowing of the coronary arteries and therefore a decreased blood supply to the heart.

1.2.4. Cerebrovascular Disease
A cerebrovascular accident or stroke is the result of an impeded blood supply to some part of the brain.

1.2.5. Inflammatory Heart Disease
Inflammation of the heart muscle (myocarditis), the membrane sac (pericarditis) which surrounds the heart, the inner lining of the heart (endocarditis) or the myocardium (heart muscle).
Advanced heart disease, like so many chronic illnesses, afflicts one individual, but affects entire families. Most people with advanced congestive heart failure (CHF) reach a point at which they need the help of a caregiver to accomplish tasks they can no longer manage alone (The Washington Home Center for Palliative Care Studies, 2002). Qualitative studies have also validated that caregiving after Coronary artery bypass graft surgery (CABG) involves direct and indirect care activities of monitoring and providing comfort and support (Hartford, 2005; Ganske, 2006).

1.3. Cancer
Ogden (2000) defines cancer as an uncontrolled growth of abnormal cells, which produces tumors called neoplasm literally means "new growth" There are two types of tumors: benign tumors, which do not spread throughout the body, and malignant tumor, which show metastasis (the process of cells breaking off from the tumor and moving elsewhere).
Holtslander & Duggleby (2009) explored the experience and processes of hope of older women who were bereaved after caring for a spouse with terminal cancer, and we develop a tentative, emerging theory of their hope experience. The participants' main concern was losing hope, which they dealt with by searching for new hope through finding balance, new perspectives, and new meaning and purpose. The emerging theory is conceptualized as a spiral within the complex social context of bereavement after caregiving.

1.4. Acquired Immunodeficiency Syndrome (AIDS)
AIDS is caused by HIV, the human immunodeficiency virus. HIV destroys the body's ability to fight off infection and disease, which can ultimately lead to death (UNAIDS, 2011). HIV is transmitted primarily via unprotected sexual intercourse (including anal and oral sex), contaminated blood transfusion, hypodermic needles, and from mother to child during pregnancy, delivery, or breastfeeding.
Boland and Sims (1996) found hope to be a component of caregiving as they attempt to capture the caregiver experiences across the illness trajectory in their qualitative study. Herth's (1993) longitudinal study defined and measured hope in family caregivers of terminally ill patients. The meaning and processes of hope have been studied across a variety of health and illness experiences, including individuals living with a terminal illness (Duggleby and Wright, 2005; Wennman-Larsen and Tishleman,2002), caregivers of persons living with chronic illness (Duggleby, Holtslander, Kylma, Duncan, Hammond and Williams,2010), caregivers of persons living with dementia (Duggleby, Williams, Wright, Bollinger, 2009; Irvin and Acton, 1997), bereaved caregivers (Holtslander, & Duggleby, 2009), and individuals living with HIV/AIDS (Kylma, 2002).
Thus, chronic illness affects not only the lives of those suffering from disease but also those of family members who care for them. Attending to the impacts of chronic illness on family members is important because the physical and emotional health of family caregivers has the potential to influence the health, welfare and successful rehabilitation of persons with such chronic illness (Han and Haley, 1999). Family members of persons with chronic illness, such as cancer, have similar distress levels as the person for whom they are caring (Cochrane & Lewis, 2005). A key psychosocial resource among family caregivers to manage and deal with their caregiving experience is hope (Borneman,Stahl, Ferrell,& Smith, 2002; Holtslander, Duggleby, Williams,& Wright, 2005). Borneman, Stahl, Ferrell & Smith (2002) in their study emphasized the importance of hope in the caregiving experience; common themes included the strong connection between hope and faith, and inter-relatedness with others.

1.5. Hope
Hope is an important psychological resource for persons with chronic illness and has been described as essential to life (Eliott & Olver 2009). Six dimensions of hope were articulated in the meta-synthesis study of the meaning of hope in nursing research (Hammer et al. 2009): living in hope, hoping for something, hope as a light on the horizon, hope as a human to human relationship, hope vs. hopelessness, and hope as weathering a storm.
Snyder's theory of hope emphasizes both "the individual desires and the strategies by which those desires are met" (Snyder, Irving & Anderson, 1991). Snyder and his colleagues (Snyder, 1989; Snyder et al., 1991) propose that there are two major, interrelated ingredients in hope. First hope is "fueled by a sense of successful goal directed determination (the agency component)" (Snyder,

Irving & Anderson, 1991). Second, hope includes a "successful sense of planning to meet one's goals (the pathways component)" (Snyder, Irving & Anderson, 1991). In other words, hope equals a positive motivational state based on the both a sense of successful goal directed energy (agency) and planning to meet one's goals (pathways) (Snyder, Irving & Anderson, 1991).

The agency component consists of the cognitive will power, determination, and energy to move toward one's goal or an individual's perceived ability to bring and continue movement towards chosen goal. Agency may be also viewed as the determination to meet personal goals and the energy for the process of negotiation (Elliott, Witty, Herrick, & Hoffman, 1991). Agency in part is based on one's history of successfully seeking and attaining goals. In other words, agency taps one's successful meeting of goals in the past, present and future (Snyder, 1994 a).

The pathways component involves the perceived ability to generate methods or avenues to accomplish one's goals. It reflects the person's perceived capacity to find a route or routes to reach a goal destination or their perceived availability of method to attain a goal (Babyak, Snyder and Yoshinobu, 1993; Snyder, 1995a). Like agency, pathways thoughts are based, in part, on a history of successfully finding one or more methods of obtaining one's goal. Pathways thoughts are enhanced by success in finding new routes to goals ones the original path is blocked. Individuals who are high in pathways thinking believe they can find multiple ways to reach goals (Snyder, 1994 b).

High- hope people are more likely to interpret stressful situations as challenging rather than threatening (Snyder, Irving & Anderson, 1991). In face of adversity, individuals with high hope have been shown to use more vigorous and diverse coping strategies including "rational action, perseverance, positive thinking, intellectual denial, restraint, self- adaptation, drawing strength from adversity and humor (Snyder, Irving & Anderson, 1991).

Low- hope people on the other hand approach goals with sense of ambivalence or even doubt, focus on falling, perceiving odds of goal attainment, and possess a negative emotional state (Snyder, 1994 a).

1.6. Rationale of the Study

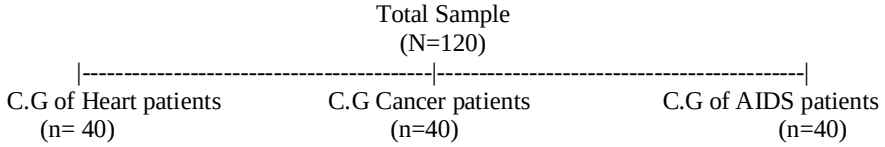
Heart, cancer and AIDS are very serious diseases rising in the world. Thus, these diseases compel many family members to assume caregivers roles. Factors, such as physical and psychological health, financial burden, limitation on freedom and social interactions (that accompany the care recipient's need for supervision), and the additional roles assumed by the most carers including those of wife, parent, spouse and employee, all contribute to carers distress. This distress therefore, affects the hope of caregivers. Many studies have been carried out on the various aspects of heart, cancer and AIDS patients. However, few comparative researches have been done on hope of caregivers of these diseased groups. In the light of above context, present research was planned and carried out with the objectives of measuring and comparing the hope of caregivers of heart, cancer and AIDS patients.

2. Method

2.1. Sample and Design

Sample of present study comprised 120 subjects, 40 each in the three groups, that is, caregivers of heart, cancer and AIDS patients. The age group of care giving's was taken with the range of 26-60 yr. Investigator took all possible precaution to ensure that no bias was involved in the selection of sample. The sample of caregivers of heart, cancer and AIDS were obtained from Escorts Heart Hospital, Okhla, Apollo Hospital, Sarita Vihar and RML Hospital and Connaught Place, New Delhi.

A diagrammatic presentation of the sample is given below:



(C.G = caregiver)

2.2. Tool Used

2.2.1. Trait Hope Scale

Hope was measured with the help of Trait Hope Scale also called as Adult hope scale developed by(Snyder, Harris, Anderson, Holleran, Irving, Sigmon, Yoshinobu, Gibb, Langelle & Harley, 1991). It is a self- report scale with twelve 8- point Likert-type item. Subjects are asked to rate each item on the extent it applies to them from 1=Definitely False, 2= Mostly False, 3=Somewhat False, 4= Slightly False, 5= Slightly True, 6 = Some What True, 7 = Mostly True, 8 = Definitely True. The Hope Scale includes two subscales, agency (perceived motivation towards goals) and pathways (perception of one's ability to produce routes to goal and to generate methods to overcome obstacles when necessary).The agency subscale includes items 2, 9, 10, 12, and the pathways sub-scale is derived from items 1, 4, 6, 8. The total Hope Scale score is derived from adding the agency and pathways items. Items 3, 5, 7, and 11 serve as distracters to obscure the content and purpose of the scale. In addition, when administrated the Hope scale is titled as Future Scale. The Hope scale has demonstrated acceptable internal reliability. The item-remainder coefficient for each item is significant ranging from .23 to .63. The coefficient alpha is reasonably high (Crobach's alphas of .74 to .84).

2.3. Procedure

This scale was administrated individually on the caregivers of heart, cancer and AIDS patients after the rapport formation. Caregivers of heart were taken from Escort hospital, Okhla, New Delhi, cancer from Apollo, Sarita Vihar, New Delhi and AIDS from Ram Manohar Lohia Hospital, New Delhi. A brief report was noted down about each caregiver concerning their miseries and how they confronted them. The participants were assured about the confidentiality of information.

3. Results

One way ANOVA & multiple comparisons of means were used to analyze the data. Obtained results are being presented in the following tables:

Group's	Sum of Squares	Df	Mean Square	F	Sig.
Between Group's	1189.217	2	594.608	6.231	0.01
Within Group's	11164.650	117	95.424		
Total	12353.867	119			

Table 1: One way ANOVA summary for Total Hope

It can be observed from table-1 that there was significant F ratio (F=6.231, p > 0.01) for total hope which indicates that there was a significant difference among the three groups of caregivers of heart, cancer and AIDS patients on total hope.

(I) Group	(J) Group	Mean Difference (I –J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
C.R Heart	C.R Cancer	.5250	2.18431	.810	-3.8009	4.8509
	C.R AIDS	6.9250(*)	2.18431	0.01	2.5991	11.2509
C.R Cancer	C.R AIDS	6.4000(*)	2.18431	0.01	2.0741	10.7259

Table 2: Post-hoc (LSD test) of various groups for Total Hope

Table – 2 reveals that there was a non-significant difference between Caregivers (C.R) of heart and cancer patients. However, significant differences were found between caregivers of heart and AIDS patients & between caregivers of cancer and AIDS patients at 0.01 levels on total hope.

Group's	Sum of Squares	Df	Mean Square	F	Sig.
Between Group's	334.517	2	167.258	6.031	0.01
Within Group's	3244.950	117	27.735		
Total	3579.467	119			

Table 3: One way ANOVA summary for Agency Subscale

It can be observed from table-3 that there was a significant F ratio (F=6.031,p < 0.01) for Agency Subscale which indicates that there was a significant difference among the three groups of caregivers of heart, cancer and AIDS patients on the agency subscale.

(I) Group	(J) Group	Mean Difference (I –J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
C.R Heart	C.R Cancer	.52500	1.17760	.657	-1.8072	2.8572
	C.R AIDS	3.77500(*)	1.17760	0.01	1.4428	6.1072
C.R Cancer	C.R AIDS	3.25000(*)	1.17760	0.01	.9178	5.5822

Table 4: Post-hoc (LSD test) of various groups for Agency Subscale

Above table –4 reveals that there was a non-significant difference among caregivers of heart and cancer patients. However, significant differences were found between caregivers of heart and aids patients & between caregivers of cancer and aids patients at 0.01 levels for Agency Subscale.

Group's	Sum of Squares	Df	Mean Square	F	Sig.
Between Group's	313.267	2	156.633	5.230	0.01
Within Group's	3504.200	117	29.950		
Total	3817.467	119			

Table 5: One way ANOVA summary for Pathway Subscale

It can be found from table – 5 that there was a significant F ratio ($F=5.230$, $p < 0.01$) on pathway subscale which indicates that there was a significant difference among the three groups of caregivers of heart, cancer and AIDS patients on the this subscale.

(I) Group	(J) Group	Mean Difference (I –J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
C.R Heart	C.R Cancer	-.50000	1.22373	.684	-2.9235	1.9235
	C.R AIDS	3.15000(*)	1.22373	0.05	.7265	5.5735
C.R Cancer	C.R AIDS	3.65000(*)	1.22373	0.01	1.2265	6.0735

Table 6: Post-hoc test (LSD test) of various groups for Pathway Subscale.

It can be found from table – 6 that there was a non-significant difference among caregivers of heart and cancer patients. However, significant differences were found between caregivers of heart and AIDS patients and between caregivers of cancer and aids patients at 0.01 levels for hope.

4. Discussion

The purpose of the present research was to study the hope of caregivers of heart, cancer and AIDS patients. Total sample of the study comprised 120 subjects, 40 in each groups i.e. caregivers of heart, cancer and AIDS patients. Data was collected from different hospitals of Delhi. ANOVA and Post-Hoc test were used to analyze the data. Results showed a significant difference between caregivers of heart and AIDS patients and between caregivers of cancer and AIDS patients on overall hope and two domains hope (i.e., agency and pathway).

Table '1' showed that there was a significant difference among caregivers of heart, cancer and AIDS patients on hope. Table-2 showed a significant difference between caregivers of heart and AIDS patients on hope. A mean difference of 6.92 was found between caregivers of heart and AIDS patients. This means that caregivers of heart scored greater than caregivers of AIDS patients on total hope. Since hope can be clearly understood by the theory of hope (Snyder, 1989) which emphasizes hope as both "the individual's desires and the strategies by which those desires are met." Individuals who scored greater than 48 on hope scale think more hopefully. To the extent a score is increasingly lower than 48, then the respondents are reporting less goal directed thinking (i.e. hope). Highest possible hope scale score is 64 while lowest possible score is 8. In present finding, caregivers of heart had greater hope than caregivers of AIDS patients. Since, AIDS is very serious disease than heart disease. So, as compared to caregivers of heart patient, caregivers of AIDS patients experienced more stress. This lead them to curiosity and confusion and thus they were not able to think strongly of many ways to get out of their problems and felt less energetic to pursue their goals. They also had feeling of not being successful in their lives. These factors, however, were not very prominently found in caregivers of heart patients. That is why caregivers of AIDS patient had lower hope than caregivers of heart patients.

Findings also showed significant difference between caregivers of cancer and AIDS patients on hope. Table-2 revealed a mean difference of 6.40 which means that caregivers of cancer patients scored greater than caregivers of AIDS patients on total hope. Stigma and fear of a negative community reaction had always surrounding the minds of caregivers of AIDS patients. They had been occupied with the thoughts like loss of income/livelihood, loss of marriage and childbearing options, poor care within the health sector, loss of reputation and thus loss of hope. Because of these thoughts their attitude was negative towards the components which actually form hope. For example, they felt less energetic to pursue their goals; they couldn't think strongly of many ways to get out of their problems, they also had feeling of not being successful in their lives. Such factors of hope were not very prominently found in caregivers of heart patients. That is why caregivers of AIDS patient had lower hope than caregivers of cancer.

A result from table- 2 showed a non- significant difference between heart and cancer caregivers on total hope. Since, both diseases heart and cancer are less stigmatized than a disease like AIDS. Further, in today's world, advanced treatments are available for curing cancer and heart disease which can increase the hope of caregivers of heart and cancer patient to the same extent.

It was found in table '3' that there was a significant difference among caregivers of heart, cancer and AIDS patients on agency hope. Post-hoc test showed significant differences between caregivers of heart and AIDS patients, and between caregivers of cancer and AIDS patients, but a non-significant difference between caregivers of heart and cancer patients.

Table-4 showed a significant difference between caregivers of heart and AIDS patients on agency hope. A mean difference of 3.77 was found between two groups of caregivers which indicated that caregivers of heart patients scored higher than caregivers of AIDS patients on agency hope. As Snyder and his colleagues (1989, 1991) proposed that there are two major, interrelated ingredients in hope. First, hope is "fueled by a sense of successful goal directed determination (the agency component)" (Snyder, Irving, & Anderson, 1991). Second, hope includes a "successful sense of planning to meet one's goals (pathways component)" (Snyder, Irving, & Anderson, 1991). The agency component consists of cognitive will power, determination and energy to move towards one's goals or an individual's perceived ability to begin and continue movement towards a chosen goal. Since, AIDS is highly stigmatized disease than heart disease. Because of stigma ridden fear and anxiety, caregivers of AIDS patients had low cognitive will power, low determination and energy to move towards their goals or low perceived ability to begin and continue movement towards a chosen goal. Therefore, caregivers of AIDS had low sense of successful goal directed determination or agency hope than caregivers of heart patients (who have good agency hope).

Findings from table-4 also showed a significant difference between caregivers of cancer and AIDS patients on agency hope. Table-4 also revealed a mean difference of 3.25 between caregivers of cancer and AIDS patients which also means that caregivers of cancer patients scored higher than caregivers of AIDS patients on agency hope. AIDS stigma exists around the world in a variety of ways, including ostracism, rejection, discrimination and avoidance of HIV/ AIDS infected people; violence against HIV/AIDS infected individuals or people who are perceived to be infected with HIV or AIDS. Not only the patients face stigma or discrimination but families of AIDS patients also face such trauma. Because of this discriminations and stigma caregivers of AIDS face more psychological problems like fear, depression, anxiety or hopelessness than other caregivers (like caregivers of cancer patient). So in such psychological trauma caregivers (of AIDS) were not in a position to pursue their goals energetically. They felt that they had not been pretty successful in their lives. Their cognitive will power and energy to move towards their goals was weak. Such factors of agency hope were not prominently found in caregivers of cancer patients, they were better on these factors. That is why caregivers of AIDS patient had lower and poor agency hope than caregivers of cancer patients.

Table-4 showed a non- significant difference between caregivers of heart and cancer patients on agency hope. Since, advanced treatments are available for curing these diseases (heart and cancer) which increase the agency hope as well as over all hope in caregivers of heart and cancer patients.

It was found in table '5' that there was a significant difference among caregivers of heart, cancer and AIDS patients on pathway subscale of hope. Post-hoc test showed significant differences between caregivers of heart and AIDS patients, and between caregivers of cancer and AIDS patients, but a non-significant difference between caregivers of heart and cancer patients.

Table- 6 showed a significant difference between caregivers of heart and AIDS patients. Table-6 also revealed a mean difference of 3.15 (between caregivers of heart and cancer patients) which indicated that caregivers of heart scored higher than caregivers of AIDS patients on pathway. Pathways is the another component of hope, which means a successful sense of planning to meet those goals (Snyder, Irving & Anderson 1991). Heart disease creates anxiety in the families of heart patient. They are anxious and threatened because of illness of their loved ones. However, they do not face the stigma which is actually faced by the caregivers of AIDS patients. Because of this stigma, caregivers of AIDS were so much occupied with anxiety that they were not able to think of many ways to get out of or solve their problems or a planning to meet their goals. Because of psychosocial trauma due to the feelings of shame, rejection or discrimination by society, their pathway scored lower than caregivers of heart patients who scored average on pathway component of hope.

Findings from table- 6 also showed significant difference between caregivers of cancer and AIDS patients on pathway. A mean difference of 3.65 was found (table-6) between two groups of caregivers which means that caregivers of cancer scored higher than caregivers of AIDS patients on pathway. As compared to the cancer, unique aspect of AIDS is the secrecy, stigma, and isolation that accompany it. Despite improvements in understanding of HIV/AIDS, families of those who are infected continue to face possible fear, rejection, and prejudice if and when their diagnosis becomes known. It is not only friends and community members who are not told of an individual's illness. Adults who are infected may not tell immediate family members or children. Cultural issues may impact communication patterns, attitudes toward HIV infection, and willingness to access social and psychological support systems. Because of such stigmatized nature of AIDS disease, its caregivers were occupied with fear which in turn reduced their agency hope or their successful sense of planning to meet their goals than caregivers of heart patients (who had better agency hope).

Table-6 further showed a non-significant difference between caregivers of heart and cancer patients on pathway component of hope. Since, both diseases heart and cancer are less stigmatized than other diseases like AIDS. Further, effective treatments are available for curing cancer as well as heart disease. This has led to the increase in long term survivors and reduced the anxiety of both patients and their caregivers, and thus increased their levels of pathway. In other words, use of advanced technology in curing both diseases have lead the respective caregivers to think of many ways to get out of or solve their problems. Such feelings had thus increased the pathways components (i.e. successful sense of planning to meet is their goals) in both groups of caregivers in similar way.

5. Conclusion

Caregiver is an act of providing concrete assistance, care and mutual support to family members or relatives who are undergoing physical, psychological or developmental problem and are not able to perform certain tasks on their own. There is strong need of caregivers in chronic diseases like heart, cancer and AIDS patients. These diseases not only create distress in the patient's life but also influence negatively care givers' life. This distress thus, affects the hope of caregivers. There was difference between caregivers of heart, cancer and AIDS patients on overall hope and agency and pathway dimensions of hope. Hope was also found to be higher in caregivers of Heart and cancer patients as compared to caregivers of AIDS patients.

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