

Hardiness and Caregiving-Satisfaction of Cancer Caregivers in Uganda

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Abstract- This study's objective was to assess the role of hardiness on caregiver satisfaction among caregivers of patients with cancer in Uganda. A cross-sectional study was carried out at Uganda Cancer Institute and Mbarara regional referral hospital between June 2019 and December 2021. Participants were informal adult caregivers of patients that had been diagnosed with cancer at the two sites. Their socio-demographic attributes were recorded using a questionnaire that was developed while scores on hardiness and caregiving satisfaction were measured using the adjusted hardiness and adjusted caregiver reaction assessment scales respectively. The tools were subjected to exploratory factor analysis. Composite indices were generated and used to determine quantitative measures of the three dimensions of hardiness and care giver satisfaction. The derived scores were then used in the subsequent analyses of the effect of hardiness on caregiver satisfaction using Stata 14 software. After controlling for all the key covariates (namely; patient's age, sex and stage of cancer; care giver's sex and , education, respondent's age, education level, country of origin, religion, and burnout), all the domains of hardiness had significant influence on the first dimension of caregiving satisfaction (i.e. $f=1.27$ and p -values= 0.2308 respectively) On the second dimension, the F-scores and p-values of commitment, challenge, and control were 1.88, and 0.0293, 1.88 and 0.0293 and 1.88 and 0.0293 respectively. In conclusion, the three domains of hardiness (commitment, control and challenge) do affect the first two aspects of caregiving satisfaction among informal caregivers in cancer care. Those with high hardiness scores are more likely to report higher levels of satisfaction while giving care to patients with cancer.

Keywords- Hardiness, Informal caregivers, caregiving satisfaction, Uganda

I. INTRODUCTION

Cancer diagnosis causes despair, hopelessness, and fear among patients and family amidst medical and economic shifts that have contributed to a rise in dependence on informal caregivers who are usually family members or close friends during periods of disease progression and treatment [1],[2],[3],[4],[5]. While cancer caregiving is a meaningful experience [6], it is associated with worsening quality of health [7], greater psychiatric related conditions, body weakness [8] and mortality in the long run among some caregivers [9]. In spite of the fact that increasing attention is being given to caregivers and affected families in cancer literature, most people are still not aware of the fact that patients and their caregivers have an interdependent relationship which consequently leads to failure in addressing the challenges of caregivers as part of the wholistic treatment strategy [10],[11],[12]. Therefore, based on the significant amount of literature, caregiver wellness is a clinical imperative with both positive and negative effects to the caregiver [12]. On the other hand, a hardy caregiver is the one who views events

that could be potentially stressful as interesting and meaningful (i.e., commitment), sees oneself as capable of changing events (i.e., control), and perceives change as normal and as an opportunity for growth (challenge) [13]. The study of hardiness dates back in 1970s when Kobasa Suggested that the three components of harness are commitment, control, and challenge [14] hence the need to carry out a study on the role of hardiness in enhancing treatment outcomes including caregiver satisfaction in cancer care is not well understood.

The paper is organized as follows. Section I contains the introduction of the study which gives background information about the study and the organization of the paper. Section II contains the related work of other scholars, details the problem statement of the study and the objectives of the study. Section III contains some of the measures undertaken to conduct the study and data analysis. Section IV contains the results of the study displayed in tables and the discussion of the results. Section V contains the conclusion which also details the recommendations of the study and areas of further

research. Section VI contains the acknowledgements whereas Section VII contains the references of the study.

II. RELATED WORK

Hardiness is composed of promoting a sense of life and peace; authority over a person's own experiences and consequences; discovering and expounding on the knowledge from life encounters [15]. Hardiness among patients with cancer is pivotal in promoting flexibility [16]. Several studies [4],[17],[18],[19] among patients with cancer and survivors demonstrate that hardiness supports in positively dealing with cancer associated agony through assertion of positive emotions and laughter that assists in reducing pain. Notably, available literature in Uganda and elsewhere suggest significant association between caregiving and health [6],[20],[21],[22]; with caregiving considered a focal driver to enhancing wellness and consequently lowering agony among patients with cancer [6], [20],[23],[24], [25],[26]. Patients with cancer through their caregivers are enabled to think through their cancer-associated traumatic encounters, and as such, may be able to get involved in avenues that may contribute to finding meaning in life, and boost their interpersonal connections [27]. Consequently, caregivers of patients with cancer obtain satisfaction from patients' positive energy and health outcomes obtained through caregiving [28], and from being made to feel that they matter and are important and also receiving words of appreciation and gratitude from those receiving care [29]. Conversely, there are limited studies available in regards to hardiness and caregiver satisfaction of informal caregivers to patients diagnosed with cancer in Uganda. The present study therefore sought to establish the role of hardiness on caregiving satisfaction among informal caregivers of patients with cancer in Uganda.

III. METHODOLOGY

Study Site and study design

This study was conducted at the Uganda Cancer Institute (UCI) in Kampala-central Uganda and Mbarara Regional Referral Hospital in south western Uganda. It was a cross sectional study by design conducted to establish the role hardiness plays on the caregiving satisfaction of informal caregivers to patients with cancer accessing care at the Uganda cancer institute in Kampala-central Uganda and Mbarara hospital which is the regional referral hospital in south western Uganda. The UCI, a public, specialised tertiary care medical facility is located on Mulago hill in Kampala. It collaborates with Makerere University School of medicine and Mulago specialised hospital which is the national referral hospital. According to the 2019 news bulletin, UCI has an in-patient service that has a bed capacity of 80 patients and it receives 200 outpatients on average daily. Mbarara regional hospital is a 600-bed capacity facility located in Mbarara district which is in south western Uganda. Mbarara satellite cancer centre at MRRH operates in collaboration with the UCI. Its establishment was as a result of the increased patient load

at the UCI with between 4500-6000 new patients being registered annually. The Mbarara regional cancer centre registers averagely 3000 new patients every year (as of March 2019, UCI news bulletin).

Sample size estimation

The sample size was calculated using the Lish and Kishlie formular basing on a related study by Hoerge et al 2016, on personality and perceived health among caregivers of lung cancer patients. The mean neuroticism score in those who perceived their health as poor (I expect my health worse) was 15.6 (5.8) and the mean neuroticism score among care givers with good health (expect my health worse) was 17.1 (5.37). Assuming that the data was normally distributed, with power of 80 and 95% significant level, the expected sample size was 436 care givers.

$$N = ((U+V)^2 * (\delta_1^2 - \delta_0^2)) / (\mu_1 - \mu_0)^2$$

$$N = 218 * 2$$

$$N = 436 \text{ participants}$$

Basing on the number of patients registered annually in Mbarara regional cancer centre (3000) and the Uganda cancer institute (6000), proportionate to size (statistics from available records) recruitment was done where at least 146 from Mbarara and at least 292 from Uganda cancer institute were included totalling to 436 participants.

Data Collection

Caregivers were identified with the help of the patient. Patients were asked to confirm whether the identified caregiver(s) were the people most involved with their care. The patients were requested to give verbal informed consent for their caregiver(s) to be approached. In cases where the care recipient was very sick and unable to identify the caregiver, the medical records were referred to for identification of the next of kin. Individuals giving care to patients with cancer were reached out to, consented verbally first and if they gave positive consent were provided with the consent form to sign and questionnaire booklet to complete. They were requested to complete the questionnaires at that point in time or at another time suitable to them in circumstances like when the caregiver was found attending to a very sick patient after which they would let the researcher know when they could be collected.

Caregivers of patients with cancer were screened and enrolled into the study if they met the inclusion criteria. They were consented verbally and in writing before enrolling on the study. The caregivers that were enrolled were the ones who did not present with any impairments cognitively after being assessed by the principal investigator. The caregiver had to be more than 18 years old and able to read and understand in English, Luganda, Swahili and Runyankole-Rukiga. The study aimed at a maximum of two contacts with the study participants. The initial contact and a second one in case the questionnaires were not completed due to justifiable reasons. To

minimize loss of participants after consenting, the research assistants kept a log book with mobile phone numbers, local addresses and alternative contact information. The study participants who developed any form of psychological distress during the research were referred to the locum clinical psychologist for further evaluation and management.

Study Participants

The study participants were consenting adult caregivers of patients with cancer (Age 18 years and above). A caregiver was defined as a not formally trained person who spends substantial amount of time caring for a cancer patient. Such a person should have played this role for at least a week.

Sampling Method

The study used convenience sampling. This was because caregivers are a mobile population and a patient could have different caregivers at any given time making it impossible to have a sampling frame. A caregiver that was found giving care at the time the researcher walked in and gave both verbal and written consent was included in the study. The consenting care givers were consecutively recruited until the sample size was accrued.

Study instruments

Adjusted Hardiness scale

The revised and shortened version of the adjusted hardiness scale developed by Paul T Bartone was used administered to measure hardiness. The adjusted hardiness scale has three subscales namely, control, commitment, and challenge[30] the items are rated on a 4 likert scale with responses; 0 “not at all true”, 1 “a little true”, 2 “quite true”, 3 “completely true”[31],[32],[33]. Different studies conducted to ascertain the validity of the shortened hardiness scale show high coefficient values of 0.78[34] and 0.83[30],[33]. This study found that this scale had three subscales; the commitment subscale had a Cronbach alpha score of 0.9937, the control scale had a Cronbach alpha of 0.9734 and the challenge scale had a Cronbach alpha score of 0.7966 which were all sufficient.

Adjusted Caregiver reaction assessment (ACRA) scale

ACRA was used to assess caregiver satisfaction. Caregiver reaction assessment scale is a 5-point scale with 7 items. The responses on this scale do range from

“strongly agree” to strongly disagree. This scale measures how caregiving impacts on an individual’s self-esteem. Questions on the instrument assess whether caregiving is rewarding and enjoyable or whether it causes resentment. Responses include statements such as; “I enjoy caring for my partner. It has construct validity [35] and regarding reliability, it has a Cronbach’s alpha of 0.9. The present study found that this particular scale had two subscales; subscale one had a reliability co-efficient of 26.46 which subscale 2 had a reliability coefficient of 48.48 which was sufficient.

Data Analysis

Statistical analysis was done using Stata version 14. The adjusted hardiness scale and adjusted caregiver reaction assessment scale were subjected to integrity structural testing using factor analysis. The structures were confirmed using confirmatory scree plots. The rotated factor loadings of the variables on the two scales were used to determine the subscales they belong to. The internal consistency of the items in each subscale was tested using Cronbach alpha co-efficient and a threshold of 75 % was used as a cut off for acceptance. Subscale distinctiveness was assessed using pairwise correlation test and a score of less than 30% was used to indicate very low correlation as guided by [36],[37],[38]. Composite indices were developed in each of the subscales and were used to do subsequent analyses. The composite indices were adjusted to begin from zero as the least and worst scenario then the maximum as the greatest and best scenario.

Composite indices were summarized using measures of central tendency and spread and the relationships between the subscales and outcome of interest which was the effect hardiness has on caregiving satisfaction was assessed using multiple linear regression modelling and group differences between the means were compared using ANOVA

IV. RESULTS AND DISCUSSION

Results

Socio-demographic features of participants; refer to table 1 in the Appendices

Table 1: Socio-demographic features of participants

Variable	Male	Female	Overall	Test stat	p-value
Age of care giver (Mean, sd)	37.3 (12.2)	33.5 (11.4)	34.7(11.8)	3.181	0.002
Age of patient (Mean, sd)	38.0 (24.1)	32.0 (22.7)	35.4(23.6)	2.506	0.013
Occupation (% , N)			-	19.114	.014
Farmer	59 (34.3)	113 (65.7)	173(39.9)		
Business	32 (28.6)	80 (71.4)	113(26.0)		
Others	49 (0.0)	98 (100)	1(0.23)		
Distance to nearest HC (% , N)			-	7.298	.199
Less than 20 Km	12164 (37.2)	228108(62.7)	349172(40.1)		
More than 20 Km	18 (24)	57 (76)	75(17.6)		
Non-Response	1 (14.2)	6 (85.7)	7(1.62)		
Education level (% , N)			-	20.730	.004

Primary level	47 (29.94)	118(70.0)	157(36.94)		
Secondary school level	50 (29.31)	97(70.69)	147(27.29)		
Completion of certificate Course	22 (37.92)	36 (62.07)	58(13.65)		
University Education	11 (40.74)	20 (59.26)	31(6.35)		
Non Response	10	30 (16.7)	40(1.39)		
Disability (% , N)			-	1.702	.427
No	136(32.5)	282(67.5)	420(97.7)		
Yes	4.0 (40)	6.0 (60)	10(2.3)		
Non Response	0 (.0)	3.0 (100)	3(0.69)		
Level income (000) (Median, range)	309710.7 (402374.1)	276182.6 (555397.6)	150000(300-5000000)	.588	0.557
Religion (% , N)			-	16.417	.006
Anglican	62 (41.6)	87 (58.4)	152(36.1)		
Roman Catholic	49 (33.3)	98 (66.7)	147(34.9)		
Moslem	5 (11.4)	39 (88.6)	44(10.5)		
Born Again	19 (26)	54 (74)	73(17.3)		
Seventh Day Adventist	1 (20)	4 (80)	5(1.2)		
Non Response	4 (30.7)	9 (69.3)	13(3.01)		
Type of CA (% , N)					
Breast Cancer	11 (31.4)	24 (68.6)	35(8.1)		
Co rectal Cancer	6 (40)	9 (60)	16(3.7)		
Prostate Cancer	13 (48.1)	14 (51.8)	27(6.2)		
Cervical Cancer	18 (27.7)	47 (72.3)	65(15.0)		
Leukaemia	28 (35.4)	51 (64.5)	80(18.5)		
Head and Neck Cancer	14 (31.8)	30 (68.2)	45(10.4)		
Childhood Cancer	2 (12.5)	14 (87.5)	16(3.7)		
Not Known	48 (31.6)	102 (68.4)	150()		
Stage of CA (% , N)			-	10.495	.033
Early Stage	37 (45.1)	45 (54.9)	82(19.3)		
Late Stage	35 (34.3)	67 (65.7)	104(24.4)		
Terminal Stage	11 (31.4)	24 (68.6)	36(8.5)		
Not Known	57 (26.1)	155(73.9)	213(47.9)		

Results show that a total of 436 care givers participated. The male female ratio was 32%:68%. The average age of the males was 37.3 sd= 12.2 compared to that of the females which was 33.5, sd= 34.7. These age differences were significant ($t= 3.181$ & $P\text{-value}= 0.002$). The majority of the care givers were from rural households (65%) followed by semi-urban (17% and urban (16%) households.

Of the 436 respondents, 94% were Ugandan, 1.4 were South Sudanese, 1.52% were Rwandese, 0.9% each were Tanzanians and Kenyans. Congolese and Burundians were 05 and 07% respectively.

Results also showed that there were significant differences in the occupation of the caregivers (test statistic of 19.1, $P=0.014$) which implies that the occupation of the caregivers influence the caregiving experience. There were significant differences between the mean and SD of the male and female peasants/farmers who formed the majority 59(42.1) and 113(38.8) with the males most influenced and the females least influenced, followed by the business people with the females most influenced 80(27.5) and males least influenced 32(22.9).

The Level of income of the caregivers was found to have a test statistic of 0.588 and a $P\text{ value} = 0.557$ which implies that there were no gender differences in the levels of income and that the level of income that a caregiver

was at was not significant and did not matter whether it was for a male or a female.

The religious affiliation of the caregivers was found to have a test statistic of 16.417 and a $P\text{ value}=0.006$ which implies that there were gender differences in the caregivers' religious affiliations and these were significant between the male and female caregivers. There was a significant difference between the means and standard deviation of the male and female caregivers of the Anglican faith 62(44.30 and 87(29.9). This indicates that males of the Anglican faith were more influenced than the females whereas the reverse was true for the roman catholic faith with males with a mean and standard deviation of 49(35.0) and females with mean and standard deviation 98(33.7).

There were gender differences among the caregivers regarding the stage of cancer that the patient being taken care of was at (test statistic of 10.495 and a $P\text{ value} = 0.033$). This implies that the stage of disease influences the caregiving differently when for males and for females. This significant difference was most pronounced in the means and standard deviation between males and females of those that did not know at which stage their patient was at 53(37.9) and 150(51.5) and least pronounced among those whose patients were terminal 11(7.9) and 24(8.2). This indicates that caregivers who did not know the stage of disease at which their patients were at were most

influenced as compared to those who knew that their patients were terminally ill.

There were no gender differences regarding the type of care provided by the caregiver (test statistic of 10.882 $P=0.144$) which implies that the type of care does not influence males and females differently.

There were gender differences regarding the relationship of the caregiver to the patient (test statistic was 19.796 P value= 0.019). This implies that there were significant differences between males and females in regards to their relationship to the patient. Results further showed that the categories of caregiver relationship most influenced were the female children of the patients with a mean of 130 and SD of 44.7 as compared to the males with a mean of 41 and SD 29.3, then followed by the siblings to the patient with female siblings most influenced with a mean of 47 and standard deviation of 16.2 as compared to the male siblings with a mean of 24 and standard deviation of 17.1 and lastly the spouses with the male spouses mostly influenced with a mean of 21, SD of 15 as compared to the female spouses with a mean of 19 and SD of 6.5.

There were no gender differences regarding the duration of care giving (test statistic of 3.183 $P=0.364$) which implies that the duration of caregiving does not influence males and females differently.

Hardiness experiences

The total mean score of the respondents on the adjusted hardiness scale was 3.17 and the standard deviation was 0.61, the total mean score for the males was 3.18 standard deviation 0.58 while that for the females was 3.16 standard deviation 0.62.

Care giving Satisfaction

The total average score of the respondents on the adjusted caregiver reaction assessment scale was 3.58. The total average score for males was 3.64 while for females it was 3.55. The standard deviation for the total ACRA scale was 0.69. The ACRA standard deviation for both males and females was 0.69.

Relationship between hardiness and caregiver satisfaction of caregivers of patients with cancer multivariate analysis level; refer to Table 2 in the appendices

Table 2: Relationship between hardiness and caregiver satisfaction of caregivers of patients with cancer multivariate analysis level.

Outcome variable	Exposure variable	Covariates adjusted for	F-statistic	P-value	R ²	Adjusted R ²	Root MSE
First dimension of caregiver satisfaction	Hardiness	Patient's age, stage of cancer, sex, age,	1.27	0.2308	0.3080	0.0658	5.7733
	Commitment	education level,	1.27	0.2308	0.3080	0.0658	5.7733
	Control Challenges	religion, country of origin of care giver, caregiver score on burnout scale and satisfaction scale	1.27	0.2308	0.3080	0.0658	5.7733
Second dimension of caregiver satisfaction	Hardiness	Patient's age, stage of cancer, sex, age,	1.88	0.0293	0.3886	0.1815	5.2859
	Commitment	education level,	1.88	0.0293	0.3886	0.1815	5.2859
	Control Challenges	religion, country of origin of care giver, caregiver score on burnout scale and satisfaction scale	1.88	0.0293	0.3886	0.1815	5.2859

Results shows that after controlling for all the covariates, all the domains of hardiness do not affect caregiving satisfaction on the first dimension of the caregiving satisfaction scale but do influence caregiving satisfaction on the second dimension of the caregiving satisfaction scale; commitment (P -value 0.0293, f statistic 1.88), control (p -value 0.0293, f statistic 1.88), challenge (p -value 0.0293, f statistic 1.88).

Discussion

This study's objective was to examine the relationship between hardiness and caregiving satisfaction. It set out to find the role hardiness plays on caregiving satisfaction of cancer caregivers in Uganda. The adjusted hardiness scale and the adjusted caregiver reaction assessment scales were used to measure hardiness and caregiving satisfaction respectively. In this study, the caregivers were selected from the Uganda Cancer Institute and Mbarara regional referral hospital. Informal caregivers of patients with cancer who were attending to patients accessing care at

the Uganda cancer institute and Mbarara regional referral hospital whether in a hospital or at home and consented to the study were recruited. Participants were purposively recruited regardless of their patient's diagnosis, stage of disease duration of illness, gender, ethnicity, education status, religion, social-economic status and position in the social structure. Participants were purposively included in the sample. They were accessed at the Uganda Cancer Institute majorly and Mbarara Regional Referral Hospital. The caregivers recruited were those accessible at the time of the study. The findings showed that all the domains of hardiness do not affect caregiving satisfaction on the first dimension of the caregiving satisfaction scale but influence caregiving satisfaction on the second dimension of the caregiving satisfaction scale. This is most likely because high hardiness enables an individual to withstand stressful situations to a great extent and thus derive satisfaction from whatever he/she does.

The findings of this study are in agreement with those of Maddi, who in her study explains that hardy caregivers possess ability to sustain positive attitudes, find ways to solve their problems, show that they have determination to change situations, and also realize and come to terms with the fact that some situations might be beyond control which helps them retain their health, happiness and remain positive towards caregiving [39].

Similarly, Studies conducted by [40], [41],[42], [43], [44], [45] revealed that there existed a positive relationship between hardiness and satisfaction. Results from their studies indicated that, higher levels of hardiness would lead individuals to experience less stress and satisfaction to a higher level. This satisfaction could be marital, work, life, or job satisfaction respectively.

The results of the present study show that Hardiness components (commitment and challenge) influence caregiving satisfaction of cancer caregivers. Results are consistent with findings that predicted that individuals with high hardiness scores (above 21.5) were happier and satisfied with life as compared to individuals with low hardiness scores (below 17.5) [46], [47].

The likely explanation for this could be explained by the transactional model of personality [48]. This model has its premises that events in an individual's life do not cause ill-health but how the situation is appraised. With this theory, it could be posited that Hardy individuals consider change to be a natural event in life, they see change as an opportunity or challenge, rather than a threat or a negative event. Individuals high on hardiness not only expect a change in their lives but also welcome it. They also look at change as having the potential to cause positive outcomes, even if the change was initially unwanted or resulted in loss or sadness. In addition, hardy individuals tend to be committed to work and activities that they are interested in tend to motivate them. Additionally, hardy people are generally more comfortable with their responsibilities than others which makes it easier for them

to accept the changes that occur as a result of taking care of their loved ones and to use the experiences gained for their betterment.

V. CONCLUSION AND FUTURE SCOPE

This study has enabled us to highlight the socio-demographic features of cancer caregivers and to determine how hardiness influences caregiving satisfaction of cancer caregivers in Uganda. The adjusted hardiness scale and the adjusted caregiver reaction assessment scales were used to measure hardiness and caregiving satisfaction. In this study, caregivers were farmers, business people and peasants by occupation. Most of the caregivers were middle age (the average age varies between 33 and 37years of age). This study has revealed that all the domains of hardiness do not influence caregiving satisfaction on the first dimension of the caregiving satisfaction scale but influence caregiving satisfaction on the second dimension of the caregiving satisfaction scale. This study has revealed that hardiness plays a role in caregiving satisfaction among cancer caregivers. With such findings, the study recommends that hardiness assessment should be done for all cancer caregivers at the beginning of caregiving. There is also need to implement hardiness training programs for all caregivers so as to enhance their caregiving satisfaction.

For future researchers, it is recommended that similar research to be conducted in a sample of child caregivers who form a significant percentage in Uganda. The new sample should consist of an equal number of male and female caregivers so as to reduce the possibility of results portraying female/male perceptions instead of cancer caregivers perceptions in general.

There is also need for longitudinal studies to examine the levels of hardiness and the effect that has on the caregiving satisfaction across the caregiving trajectory right from diagnosis to demise and through survivorship in order to provide a clearer understanding of the progress of hardiness of the caregivers. The studies will help to identify critical points like diagnosis or relapse at which distress among caregivers is likely to increase and as well as define critical time points for optimal hardiness interventions.

This study's limitations are that being cross-sectional by design the exposure and outcome are simultaneously assessed hence there is generally no evidence of a temporal relationship between exposure and outcome. Without longitudinal data, it is not possible to establish a true cause and effect relationship. The sample also consisted of a majority of females (68%) against only 32 percent of males. The results cannot be freely generalised to the population as they can possibly be labelled as explaining/representing the 'female cancer caregivers' hardiness and caregiving satisfaction rather than that of cancer caregivers in general.

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