

8 I Z B S F 5 I F J S / F F E T / F H M F D U F E 4 P V S D F  
\$ P M P S F D U B M \$ B O D F S 4 V S W J W P S T 5 I F J S  
4 U S B U F H J F T U I F Z & N Q M P Z F E

Augustus Nyakundi\* <sup>1</sup> and Joyce Makumi <sup>2</sup>

<sup>1</sup>Chuka University, Chuka, Kenya

<sup>2</sup>

presented by the survivor to the oncologist end up being addressed while the caregiver's needs are not taken care of. Varvogli & Darviri (2011) observe that patients and families who are able to use effective or healthy coping strategies such as relaxation and stress management techniques to deal with stress reactions have been shown to have lower levels of depression, anxiety, and symptoms related to the cancer diagnosis and its treatment [21].

Averyt & Nishimoto (2014) and Grant et al. observe that colorectal cancer survivors with colostomy, and their caregivers should be monitored for psychosocial concerns on a regular basis and health care providers should tailor care based on individual patients' and the family caregivers' needs [11,12]. Grant et al. concluded that approaches of survivorship, care and psychosocial interventions in colorectal cancer survivors with colostomy, should take into account family caregivers' needs and gender specific concerns and requirements to aid in adjustment [12].

## Statement of the problem

Caregivers can determine the outcomes of the disease treatment and management process. They are an important stakeholder in the healthcare sector, not just for individual patients but also to the health of the general population. However, their needs are often neglected. This study focused on caregivers of patients who had survived colorectal cancer and who regularly attended a colorectal cancer support group meeting organized by Stoma World Kenya in Nairobi. These caregivers bore the burden of both the physical and psychosocial effects of colorectal cancer, leading to high levels of post-traumatic stress reactions which are normally not addressed [15]. Further Radecki et al. (2014) noted that, in both the family caregivers and the patient, depression, anger, anxiety, insomnia, feelings of worthlessness, attitudes of hopelessness and reduced self-esteem frequently accompany cancer diagnosis, treatment and rehabilitation [16]. This is negatively influenced by family dynamics and coping mechanisms leading to counselling needs among the patients and their caregivers. The treatment outcomes and quality of life for both patients and family caregivers is determined by the coping methods they utilize whether action oriented or intrapersonal, psychic, to minimize the trauma associated with a cancer diagnosis and subsequent treatment [15]. With incidences of cancer prevalence increasing in Kenya, many families are expected to take care of their members who have been diagnosed with cancer. The quality of care given by family caregivers is dependent on their level of preparedness and state of mind. There is therefore need to find out the sources of stress for caregivers of colorectal cancer survivors, their stress reactions and coping strategies in order to suggest more effective ways of taking care of their needs.

## Literature Review

A number of studies demonstrate that a cancer diagnosis affects the mental health of the patient and their family members and caregivers with depression, stress reactions and anxiety, impaired family relationships characterized by decreased communication and intimacy being common [9,17]. Stress reactions and anxiety are particularly common when cancer is diagnosed at advanced stages, and this is devastating and creates weighty strain in personal and family life [17,18].

Family caregivers of colorectal cancer survivors are poorly prepared to cope with the nature of the disease and long complex treatment regimens [19]. As clinicians focus on the physical symptoms and the need to aggressively treat the affected patient, the emotional and psychosocial trauma caused by the disease and treatment to the family caregiver is often overlooked [19]. Family caregivers often face a range of stressors, including occupational and financial strain as some have to abandon their own formal employment to take care of the affected family member, change in family roles and disrupted household routines leading to anxiety and stress reactions that are often neglected by oncologists and other health care [20].

are able to use effective or healthy coping strategies such as relaxation and stress management techniques to deal with stress reactions have been shown to have lower levels of depression, anxiety, and symptoms related to the cancer diagnosis and its treatment [21].

There is no evidence that successful management of psychological stress improves cancer survival, it certainly does improve the quality of life to both the patient and the caregiver [22].

### Coping strategies

Saidi et al. (2010) postulates that colostomy formation which is part of surgical treatment of colorectal cancer results in the loss of an important body function [23]. This adversely affects the quality of life of both the patient and caregiver. Whenever there is unexpected waste collection, the caregiver has to attend to the patient who is immobile, and this may result in long-term consequences such as disturbed sleep and enormous challenges for personal hygiene and care [23]. Colostomy formation and care has psychological and social consequences that can be complex and persistent for both the caregiver and patient, requiring psychosocial interventions which need regular monitoring and tailored care [23]. They added that approaches of survivorship care and psychosocial interventions in colorectal cancer survivors with colostomy, should take into account gender specific concerns and requirements to aid adjustment.

Several studies have described various coping strategies for patients of colorectal cancer and family caregivers to reduce the levels of depression, anxiety, and symptoms from treatments and cope with associated psychological stress. These strategies include meditation, relaxation, counselling, exercise, cognitive behavioural therapy, joining support groups, educating others about the disease, participating in colorectal cancer research, information gathering from the internet, changing lifestyle patterns and seeking alternative treatment options, having a high self-esteem, realistic optimism, the ability to find meaning even in traumatic experiences, the tendency to perceive stressful events in less threatening ways and the ability to reframe adverse experiences in a more positive light [24-26,22].

Cancer family caregivers are a unique population whose needs are often superseded by those of the ill family member [27]. While for some caregivers the experience is largely gratifying and positive, for others it is a source of stress and negative emotions [27]. Some studies report caregivers expressed the belief that they must maintain a shroud of silence around all negative emotions and doubts [27].

According to Williams, Van Ness, Dixon & McCorkle (2012), the degree to which caregiver burden is experienced depends on a number of factors which can be attributed to both caregiver and patient characteristics [28]. They further identified predictors which include caregiver demographic factors such as age, gender and relationship with patient, as well as caregiver's health status which contribute to the degree to which the caregiver experiences the stress reactions. The severity of symptoms is another key determinant of the caregivers' burden [29].

Cobb et al. found that there are limited studies that have evaluated the impact of a colorectal cancer diagnosis on the family caregivers [30]. They also found that the majority of caregiving research has focused on negative aspects of caregiving such as caregiver burden, stress, psychological distress, depression, strain, and demands. The positive aspects which include preparedness, confidence, benefits, esteem, and resilience have not been addressed.

Williams & Bakitas (2012) observe that informal caregivers play a role of growing importance in providing optimal health care to

patients with oncology and other chronic illnesses [29]. They also state that, though caregiving is a challenging role, it can also potentially have positive aspects for the caregiver. Williams & Bakitas (2012) and Cobb et al. conclude that caregiving also has cultural aspects which have not been well explored [29,30].

#### Theoretical framework

Theories of coping strategies: Coping has been defined as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person [31]. Research has distinguished between problem-focused and emotion-focused coping with Blum & Sherman (2010) and Mosher et al. suggesting that problem-focused coping is directed at managing or altering the problem causing the distress when stressful encounters are appraised as responsive to change [31,32], while Mello et al. observe that emotion-focused coping consists of actions or thoughts to control the undesirable feelings that result from stressful circumstances and more often occurs through avoidance distancing and selective attention [33].

#### Cognitive Behavioural Family therapy

Cognitive behavioural family therapy aims to help people become aware of their negative patterns of thinking, their interpretations, and the behavioural patterns which reinforce distorted thinking, leading to stress reactions. This therapy helps people to develop alternative ways of thinking and behaving which aim to reduce their psychological distress. Family caregivers of patients with cancer and cancer survivors report a number of psychological complaints, such as anxiety and depression and physical grievances because of the burden associated with providing care [34].

The principles of cognitive behavioural family therapy by Dattilio (1993) are useful when counselling the family caregivers of the colorectal cancer survivors according to their identified counselling needs [35]. Mia et al. stated that this is a form of psychotherapy that combines cognitive therapy, a type of talk therapy that seeks to identify and help change self-destructive thought patterns, with behaviour therapy, an approach that assists people to identify unhealthy beliefs and behaviours and replace them with positive ones [34]. Cognitive behaviour therapy has been shown to be effective in other Post Traumatic Stress Disorder populations and also for cancer-related adjustment problems such as anxiety [36].

#### Conceptual framework (Figure 1)

Variable: Psychological stress reactions and coping strategies represent the independent variables. Demographic factors such as finances, gender, age, education level, employment status, marital status, and stage of colorectal cancer the survivor is at, are intervening variables. Counselling needs were considered as dependent variables.

This study concentrated on the gender, age, education level, employment status and marital status of the respondents, to establish how to reduce distress. Counselling that is directly related to

face-to-face interviews were conducted with 20 caregivers who were proficient in English. For the questionnaire, a Likert scale was used, thus developing a sense of obligation that caregiving is an inborn trait and a source of fulfillment of their natural role [40]. In a study done by Longacre (2013), she found that a significantly higher percentage of female caregivers reported needing more information pertinent to the care of colorectal cancer survivors.

Attitude of coping with stress inventory (ACSI) modified tool invented by Lazarus & Folkman (1984) was utilized [38]. They observed that individuals deal with stress in two basic ways: in problem-focused coping, where they directly address the threat by trying to change the situation; and in emotion-focused coping, where they try to make themselves feel better about the threat.

The modified tool used in the study had 22 psychometric responses, with Likert scale ranging 1-5, where '5' indicated the family caregivers who were 'extremely affected' and '1' those who were 'not affected at all'. This tool consisted of Intrusion, Hyper-arousal, Avoidance and Social Support subscales. A modified structured question sheet was used as a guidance for face-to-face interviews of the group that was not proficient in English [39].

### Instrument pretesting

In order to ensure the reliability and validity of the data collection instruments, 3 questionnaires and interview schedules were tried out to a group of randomly selected respondents of family caregivers of colorectal cancer survivors who were proficient in English and present for the support group meeting when the pretesting study was carried out. These did not participate in the actual study.

### Data analysis

Thematic analysis was used to analyse the data collected. The themes discussed in this study were the information needs and sources as coping strategies against stress for caregivers of colorectal cancer survivors. The quantitative data obtained was analyzed using Microsoft Excel spreadsheet and was presented using frequency distribution tables.

### Ethical Considerations

An informed consent was obtained from the respondents and informants. The informed consent explained the study's purpose, procedures, risks and benefits, as well as assurances about the participants' confidentiality. A research permit (Ref. NACOSTI/P/18/91818/23912) was obtained from the National Commission for Science, Technology and Innovation (NACOSTI), the government agency charged with approving research in Kenya. The ethical and governance body of the Aga Khan University Hospital granted permission for the study (Ref. 2018/REC-76 v1). As required by the Aga Khan University Hospital, a member of their staff assisted with administering the questionnaires and organizing the face-to-face interviews.

### Findings and Discussion

#### Descriptive analysis

The survey questionnaire was distributed to the colorectal cancer survivors' caregivers who were proficient in English. There were 20 caregivers who responded to the questionnaire (Table 1).

Table 1 above illustrates that out of the 20 questionnaire respondents, 5 were male constituting 25% of the respondents while 15 were female, constituting 75%. This shows that most of the family caregivers were females. Robinson, Bottor, Pesut, Olie & Tomlinson (2014) explain that male caregivers experience societal pressure to



	Not at all	A little bit	moderately	Quite a bit	Extremely	Total
Felt irritable and angry	1	1	1	4	13	20
: DV M X P S \ D Q G V W D U W O H Ø		1	2	9	6	20
Trouble sleeping	0	2	3	8	7	20
Trouble concentrating	0	4	2	7	7	20
Reminders caused me physical reactions	0	1	6	10	3	20
: DV Z D W F K I X O D Q G R Q J X D Ø G		1	2	5	12	20
Total	3	10	16	43	48	120

Table 7: Stress Reactions on Hyper Arousal Scale.

	Not at all	A little bit	Moderately	Quite a bit	Extremely	Total
Away from reminders	4	2	1	3	10	20
Tried not to think about it	0	3	5	10	2	20
: DV D Z D U H K D G I H H O L Q J V D Ø R X W L W		1	3	8	7	20
Feeling numb about diagnosis and treatment	1	2	3	5	9	20
Tried to remove experience from memory	2	0	1	9	8	20
Tried not to think about it.	2	2	2	5	9	20
Total	10	10	15	40	45	120

Table 8: Coping Strategies on Avoidance Scale.

	Not at all	A little bit	Moderately	Quite a bit	Extremely	Total
Talked to someone for more information.	2	3	0	5	10	20
Asked a relative or friend for advice.	2	3	3	5	7	20
Talked to someone about my feelings	3	1	4	4	8	20
Talk to someone for help about side effects.	3	1	2	8	6	20
Got professional help.	12	4	2	0	2	20
Total	22	12	11	22	33	100

Table 9: Coping strategies on seeking social support.

Relationship	No.
Spouses	5
Brothers	2
Sisters	1
Son	2
Daughters	2
Mothers	3
Father	1
Hired	4
Total	20

Table 10: Relationship with the survivor.

(n=8) said no, while 15% (n=3) did not respond. Further, 40% (n=8) who had not been involved when diagnosis of colon cancer was made, reported to have been involved when the survivor was being discharged from the hospital. By not involving caregivers in discussions about their patients' diagnosis, oncologists and nurses were denying the caregivers critical information that could enable them take care of the patient more effectively. Longacre (2013) observes that information needs of cancer caregivers and their own personal needs have to be accounted for, to ensure proper continued support and care of the survivor at discharge [41].

Table 12 above illustrates the family caregivers' responses to their source of information on how to care for the survivors. The responses were as follows: 20% (n=5) learnt through their friends, 20% (n=5) from the Internet, 20% (n=5) from fellow patients from the support group, 20% (n=5) from NGOs and 12% (n=3) learnt from doctors and nurses at the point of discharge, 4% (n=1) struggled to get information and 4% (n=1) had no information from any source. Friends, the

Internet, fellow patients from the support groups, and NGOs provided information to more family caregivers than the doctors and nurses. Some respondents obtained information from more than one of the sources. Information needs and the need for psychosocial support are intertwined. To reduce possible stress reactions and to be able to offer better care and management to the patients, caregivers need adequate and reliable information. This study emphasizes the need for a framework through which caregivers can call or visit the hospital whenever they have questions or are facing a crisis [48].

Table 13 above illustrates the family caregivers' responses to their source of support for caring for the survivor with 25% (n=5) saying support came from their friends, 25% (n=5) from NGOs, and 50% (n=10) from their relatives (extended members of family). Evidence that caregivers get assistance from social support networks in caring for their patients are an indication that caregiving is a communal responsibility. It is never fully left to an individual or a family. This makes the burden of stress on the caregiver lighter. However, the fact that caregivers did not list healthcare personnel as part of their source of support shows that a more successful surgery for cancer and completion of chemotherapy and related treatments, it is assumed that the family has adjusted enough to cope with the physical changes that colorectal cancer and its treatment brings. There is need for continued counselling and support long after completion of treatment. Caregivers need counselling support to deal with the altered self-image of the patient. Some of the physical and psychological changes from cancer treatment may become pronounced when the patient goes back to his or her family, thus the need to continue with supportive counselling at community level within the context of support groups (Cobb et al. 2016) [30].

Responses	No.
Yes	9
No	8
No response	3
Total	20

Table 11: Caregiver's involvement in diagnosis and treatment.

Sources of information	No.
Friends	5
Internet	5
Patient	5
NGOs	5
Doctors & Nurses	3
Struggling to know	1
None	1

Table 12: Sources of information for caregivers.

Sources of Support	No.
Friends	5
NGOs	5
Relatives	10

Table 13: Sources of support for caregivers. Sources of j --[.2n q 0 11.039 l z2.5197 464.923705 634.6059 cm 0 0 m 0 11.0 0 0 1 1692.5197 464.923705 634.6

--	--

19. Deshields TL, Potter P, Olsen S, Liu J (2014) The persistence of symptom burden: symptom experience and quality of life of cancer patients across one year. *Supportive Care Cancer* 22: 1089-1096.
20. Mosher CE, Bakas T, Champion VL (2013) Physical health, mental health, and life changes among family caregivers of patients with lung cancer. *Oncol Nurs Forum* 40: 53-61.
21. Varvogli L, Darviri C (2011) Stress Management Techniques: evidence-based procedures that reduce stress and promote health. *Health science journal* 5: 74-89.
22. Johnston MC, Porteous T, Crilly MA, Burton CD, Elliott A, et al. (2015) Physical and study methods. *Psychosomatics* 56: 168-180.
23. Saidi H, Nyaim E, Githaiga J, Karuri D (2010) CRC surgery trends in Kenya. *East African Medical Journal* 87: 10-15.
24. Moreno-Smith M, Lutgendorf SK, Sood AK (2010) Impact of stress on cancer metastasis. *Future Oncol* 6: 1863-1881.
25. \$VLHGX \*% (XVWDFH 5: (WRQ '7 %UHLWNRSI & 5  
A qualitative exploration with patients and their family members. *Family Practice* 31: 598-606.
26. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J, et al. (2014) Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *J Pain Symptom Manage* 47: 1064-1077.
27. :LOOLDPV \$ 0F&RUNOH 5 &DQFHU IDPLO \ FDU HJLYHUV GXULQJ WK SDOOLDWLYH  
hospice, and bereavement phases: A review of the descriptive psychosocial literature. *Palliat Support Care* 9: 315-325.
28. :LOOLDPV \$ 9DQ 1HVV 3+ 'L[RQ - 0F &RUNOH 5  
by gender and age among cancer family caregivers. *Nurs Research* 61: 22-27.
29. :LOOLDPV \$ %DNLWDV 0 &DQFHU )DPLO \ &DU HJLYHUV \$ THZ LUHFWRU TRU  
Interventions. *J Palliat Med* 15: 775-783.
30. &REE 6& (WNLQV / 1HOVRQ 0 (JOHVWRQ % 6ZHHQ & HW DO &DUHJLYHU  
Reactions in Oncology and Other Chronic Illnesses. *Oncol Nurs Forum* 43: 321-327.
31. Blum K, Sherman D (2010) Understanding the experience of caregivers: A focus on transitions. *Semin Oncol Nurs* 26: 243-258.
32. Mosher CE, Champion VL, Hanna N, Jalal SI, Fakiris AJ, et al. (2013) Support service use and interest in support services among distressed family caregivers of lung cancer patients. *Psycho oncol* 22: 1549-1556.
33. Mello S, Tan AS, Armstrong K, Sanford J, Robert CH, et al. (2014) Anxiety and depression among cancer survivors: the role of engagement with sources of emotional support information. *Health Commune* 28: 389-396.
34. Mia S, O'Toole R, Zachariae R, Renna ME, Mennin DS, et al. (2017) Cognitive behavioral therapies for informal caregivers of patients with cancer and cancer survivors: A systematic review and meta-analysis. *Psycho oncol* 26: 428-437.
35. Dattilio F (1993) Cognitive Techniques with Couples and Families. *The Family Journal* 1: 51-65.
36. Hofmann SG, Asnaani A, Vonk IJJ, Sawyer AT, Fang A, et al. (2012) The HI FDF \ RI FRJQLWLYH EHKDYLRXUDO WKHUDS \ D  
36: 427-440.
37. Frels RK, Onwuegbuzie AJ (2013) Administering quantitative instruments with 4XDOLWDWLYH QWHUYLYHZV \$ PLIHG UHVHDUFK DS  
4XDOLWDWLYH RI UHVLOLHQFH GHQLWLRQV  
43: 427-440.
38. Lazarus RS, Folkman S (1984) Stress, appraisal and coping. New York: 6SULQJHU 3XEOLVKLQJ &RPSDQ \ ,QF \$ 6FLHQWL¿F  
6SULQJHU 3XEOLVKLQJ &RPSDQ \ ,QF \$ 6FLHQWL¿F
39. 7HXIHO 6KRQH 1, :LOOLDP 6 )RFXV \*URXSV L  
*Chronic Disease* 7: 67.
40. Robinson C, Bortoff J, Pesut B, Oliffe J, Tomlinson J (2014) The male face of caregiving: A coping review of bereavement for a person with dementia. *Am J Men's Health* 8: 409-426.
41. Longacre M (2013) Cancer Caregivers Information Needs and Resource Preferences. *J Cancer Educ* 28: 297-305.
42. Li H, Stewart BJ, Imle MA, Archbold PG, Felver L, et al. (2000) Families and hospitalized elders: A typology of family care actions. *Res Nurs Health* 23: 3-16.
43. Petronio S, Sargent J, Andea L, Reganis P, Cichocki D, et al. (2004) Family DQG IULHQGV DV KHDOWKFDUH DGYRFDWHV GLOHP  
Soc Pers Relat 21: 33-52.
44. Ayse C, Ilknur AA, Figen C (2017) Experiences of Caregivers with Spouses Receiving Chemotherapy for Colorectal Cancer and their Expectations from Nursing Services. *Asia Pac J Oncology Nurs* 4: 173-179.
45. Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, et al. (2016) Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity. *Support Care Cancer* 24: 1975.
46. Zabalegui A, Cabrera E, Navarro M, Cebria MI (2013) Perceived social support and coping strategies in advanced cancer patients. *Journal of Research in Nursing* 18: 409-420.
47. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS, et al. (2014) Caregiver Burden A Clinical Review. *JAMA* 311: 1052-1060.
48. Cormio C, Romito F, Viscanti G, Turaccio M, Lorusso V, et al. (2014) Psychological well-being and posttraumatic growth in caregivers of cancer patients. *Front Psychol* 5: 1342.