

Why are Their Needs Neglected? Sources of Stress for Caregivers of Colorectal Cancer Survivors, Their Stress Reactions and the Coping Strategies they Employed

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Abstract

Incidences of cancer prevalence are on the rise in Kenya. Studies have shown that as a result of cancer diagnosis, treatment and management experiences, cancer patients and caregivers endure significant levels of stress. Whereas healthcare personnel focus their attention on reducing the physical and emotional pain the cancer patient is exposed to, often the caregivers' needs are neglected. Yet, the caregiver is a valuable partner in determining the treatment and management outcomes of the cancer patient as well as increasing knowledge about cancer prevention, treatment and management among the general population. This study sought to establish the sources of stress among caregivers of colorectal cancer patients in a hospital in Nairobi and the coping strategies they commonly used to overcome the stress. It was found that the majority of the caregivers of colorectal cancer patients were spouses. Besides the sources of stress identified in various studies, others included lack of information about a patient's diagnosis, exclusion from decision-making on treatment, the high cost of colorectal cancer treatment, stigma, exhaustion and burnout. Their stress reactions included irritability and anger. Among the coping strategies the caregivers used included avoidance of events and thoughts associated with the cancer diagnosis, pain and treatment; and getting information and support from family members, friends, support group members and the Internet. It was found that there was no formal framework for healthcare professionals engaging caregivers. The most alienated caregivers were those not proficient in English. Since these were also likely to have limited sources of information, their levels of stress were likely to be higher than those who were proficient in English.

Keywords: Colorectal Cancer; Survivors; Caregivers; Coping Strategies; Counselling Needs

Background to the Study

Cancer is the third leading cause of death in Kenya with over 40,000 new cases and 27,000 deaths reported annually [1,2]. The top five cancers in Kenya include breast, cervical, prostate, head and neck cancers, and gastro-intestinal cancers which include colorectal cancer [2].

Colorectal cancer is a cancer affecting the large bowel or the rectum whose incidence and death rates is rising rapidly in many low-income and middle-income patients in countries like Kenya [3]. Colorectal cancer risk factors include family history where individuals have a genetic predisposition, lifestyle factors such as diets high in red or processed meat and low in fruits and roughage, alcohol consumption, obesity and lack of exercise [4]. Colorectal cancer is a serious contributor to disease morbidity and mortality in Kenya and other nations. According to the World Health Organization (2018), there were 1.8 million incidences of colorectal cancer worldwide with mortality being at 881, 000 per year [5]. Unfortunately, only about a third of colorectal cancers are diagnosed at an early stage [6].

Extensive family coping studies have been conducted among family caregivers dealing with a broad range of cancers. However, in colorectal cancer the family caregivers' literature has mainly reported on the impact of the diagnosis on the psychological sickness [7] and screening [8], with few studies reporting on the coping experiences of caregivers [9]. Traa, De Vries, Roukema, Rutten & Den (2014) report that, caregivers of patients with colorectal cancer experience psychological and social challenges related to the burden of caregiving [10].

According to Averyt & Nishimoto (2014), patients with colorectal cancer often end up with an artificial surgical opening, called colostomy

for elimination of stool [11]. This causes profound challenges for the caregivers, often members of the family, not well prepared and trained to deal with the medical device the patient is using for elimination of stool. Though colostomy creation is regarded as a lifesaving surgery, studies have consistently reported low quality of life to the survivors thereafter and the caregivers are equally affected by this physical alteration to the survivor [11,12]. This results in substantive changes, not only in bodily appearance and functional ability, but also in the overall personal hygiene of the survivor. The family caregiver gets affected in the process of giving care, thus ending up with psychological stress reactions which on the normal circumstances are not readily addressed by the oncology nurses or the oncologists.

As the patient's pain control is taken care of, attention to the needs of the caregivers is often neglected [13]. A decrease in the ability to communicate with the spouse as an immediate caregiver poses a general negative change in the overall marital relationship. Incidences of marital discord, include sexual problems, when caregivers of colorectal cancer patients are spouses [13].

Colorectal cancer patients complain about family difficulties ranging from resentment surrounding the patient's extensive use of bathrooms, to a loss of respect from their spouses and marked sexual impairment, including [14]. In the clinics, all these grievances

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presented by the survivor to the oncologist end up being addressed while the caregiver's needs are not taken care of.

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 negatively influences 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 intrapsychic, 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 relations 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].

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]. Though 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 whether there was any difference on the sources of stress they had, information needs and information sources and the strategies they used to cope with their stress reactions, hence their counselling needs.

Methodology

The study used a mixed methods approach to target respondents drawn from caregivers of colorectal cancer survivors who had a monthly support group meeting at The Aga Khan University Hospital in Nairobi, Kenya. The group was established in 2010 to provide psychological and emotional support to newly diagnosed colorectal cancer patients and their families (www.fowc.ca>Stoma-World-Kenya). The mixed methods approach involved collecting information by face-to-face interviews for qualitative data, targeting those who were not proficient in English, and administering questionnaires to the caregivers who were proficient in English to generate quantitative data [37].

The caregivers normally accompanied the survivors to the monthly support group meeting or to the outpatient clinics for follow up and treatment. There were about 968 registered participants in this support group with 700 being colorectal cancer survivors and 268 being caregivers (www.fowc.ca>Stoma-World-Kenya). During support group meetings on any given month, an average of 30 survivors and between 15 to 20 caregivers attended the forum, making a total of about 45 to 50 participants. The study was done at the Aga Khan University Hospital in Nairobi using purposive sampling as it was the only hospital with a dedicated colorectal cancer survivors' support group (Stoma World Kenya) in the country. A sample size of 40 caregivers participated in the study. The respondents were selected using non-probability random sampling.

Data collection tools

Self-administered questionnaires were issued to 20 of the caregivers of the colorectal cancer survivors who were English proficient while

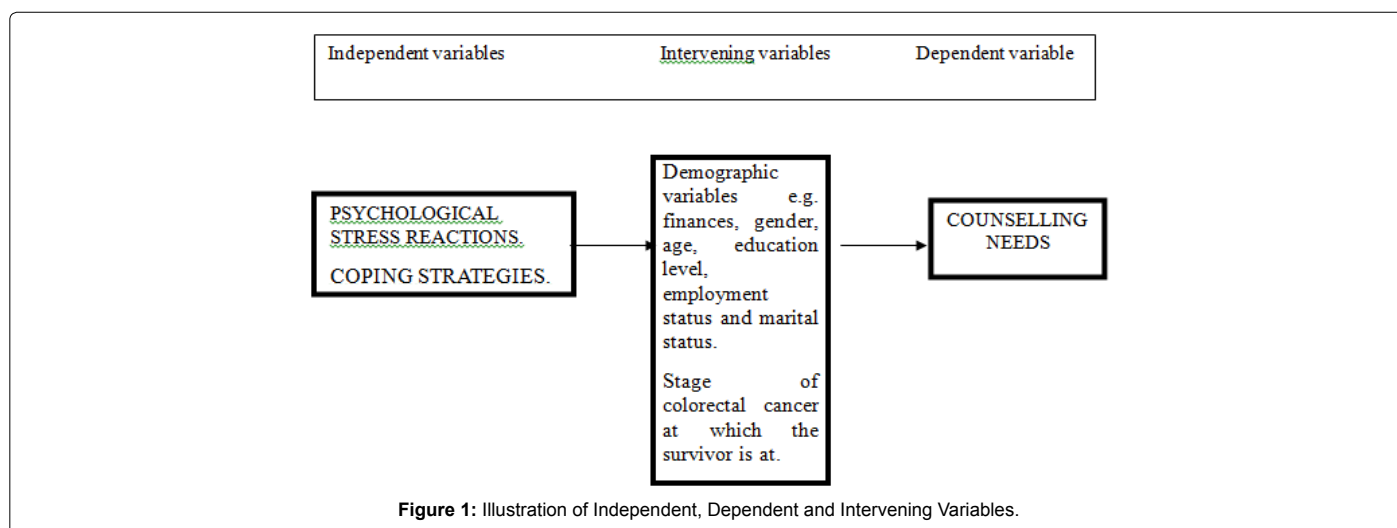


Figure 1: Illustration of Independent, Dependent and Intervening Variables.

face-to-face interviews were conducted with 20 caregivers who were not proficient in English. For the questionnaire, a Likert scale was utilised. The questionnaire focused on the variables reflecting the study's main purpose and their dimensions which were information needs and sources, sources of stress and coping strategies among family care givers 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 spread sheet 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, Bottorff, Pesut, Oliffe & Tomlinson (2014) explain that male caregivers experience societal pressure to

uphold masculinity while women learn their gender role as they grow up, thus developing a sense of obligation that caregiving is an inborn trait and a source of fulfilment of their natural role [40]. In a study done by Longacre (2013), she found that a significantly higher percentage of male caregivers reported needing more information pertinent to providing direct care than females [41]. As a way of coping, men desired to be given more information so that they could take care of the survivor better. Heightened emotional burden places caregivers at risk of poorer health outcomes, including decreased immune function and greater risk of heart diseases [41]. This also validates the argument that gender influences coping strategies.

Table 2 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, Bottorff, Pesut, Oliffe & Tomlinson (2014) explain that male caregivers experience societal pressure to uphold masculinity while women learn their gender role as they grow up, thus developing a sense of obligation that caregiving is an inborn trait and a source of fulfilment of their natural role [40]. In a study done by Longacre (2013), she found that a significantly higher percentage of male caregivers reported needing more information pertinent to providing direct care than females [41]. As a way of coping, men desired to be given more information so that they could take care of the survivor better. Heightened emotional burden places caregivers at risk of poorer health outcomes, including decreased immune function and greater risk of heart diseases [41]. This also validates the argument that gender influences coping strategies.

Table 3 above illustrates the respondents' level of education. Caregivers with low levels of education are more likely to experience a heavier burden in their duties because of a number of factors including lack of awareness of some sources of information, inability to access some sources of information, difficulties in comprehending either verbal or written information that is in a language they are not proficient in. With higher levels of education, it will be easier for family caregivers to fulfil their functions of exchanging information among all parties; interpreting language; offering additional viewpoints, explanations, interpretations of medical diagnoses; collaborating to offer personal care to the patient and learning technical procedures; taking part in therapeutic regimens; and encouraging patients to comply with their medical treatments [42-44].

Gender	No of people	Percentage
Male	5	25%
Female	15	75%

Table 1: Gender distribution of the respondents.

Age Bracket(Years)	No. Of People	Percentage
18-25	0	0%
26-30	2	10%
31-35	0	0%
36-40	3	15%
41-50	6	30%
Above 50	9	45%

Table 2: Age bracket of the respondents.

Education	No of people	Percentage
Primary	6	30%
Secondary	5	25%
Tertiary	9	45%

Table 3: Education level of the respondents.

Table 4 above illustrates the marital status of the respondents. With the highest number of respondents being married, the findings show that cancer and its treatment affected both the patients and the spouses who were involved in care giving. This is in agreement with Ayse, Illknur, Aydin & Figen (2017) who observe that spouses of the survivors of colorectal cancer bear the greatest responsibility of the care that the survivor requires, causing stress reactions and need for early psychological support [44].

Table 5 shows the employment status of the respondents. With 85% of caregivers being unemployed, it was likely that they had more sources of stress, especially due to lack of income. Caregiving negatively affects employment because of the many needs of the patient, including frequent visits to the hospital which often require time off from work. This causes difficult relationships with employers, leading to loss of employment further complicating the patient and caregivers' emotional state.

Table 6 summarizes the responses that were received regarding Stress Reactions on Intrusion of thoughts among the respondents. According to the findings, 36% were extremely affected, 33% were quite a bit affected, and 16% were moderately affected as they experienced intrusions of thoughts of the painful moments that the cancer patients they were taking care of had to go through. At varying percentages, the caregivers experienced trouble sleeping, avoided getting upset, and dreamt about their patients' diagnosis and treatment. Rumpold, Schur & Amering (2016) had similar findings that care giving is associated with high levels of distress and stress intrusion, requiring counselling interventions which are not offered to the caregivers [45].

Table 7 above refers to stress reactions on hyper arousal scale of the respondents. In this respect, those who were extremely affected, 27% (n=13) of the respondents felt irritable and angry due to the thoughts of the treatment process of the patients they were caring for; 12.5% (n=6) felt jumpy and easily startled; 14.6% (n=7) had trouble falling asleep; 14.6% (n=7) had trouble concentrating; 6.3% (n=3) experienced physical reactions caused by the reminders of the process, and 25% (n=12) felt watchful and on-guard. This demonstrated that caregivers do have stress reactions that require to be addressed.

Table 8 above shows how the caregivers indicated their efforts to avoid or evade the feelings of stress that kept on haunting them due to

traumatic experiences of the patients that they were taking care of, as a coping strategy. According to the research findings, the majority of the respondents, 38% (n=45), had extremely attempted to get rid of the experience of diagnosis and treatment of their colorectal cancer patients from their memory using various forms of avoidance. Avoidance has also been reported as one of the coping strategies among caregivers by Zabalegui, Cabrera, Navarro & Cebria (2013), further eliciting the need for counselling and support [46].

Table 9 above illustrates how the respondents sought for psycho-social support regarding their post-traumatic experiences. For those who were extremely affected totalling to 33% (n=33) of the respondents, 30.3% (n=10) talked to someone to find more about the experiences they had with their patients, 21.2% (n=7) asked relatives and friends that they could trust to advise and 24.2% (n=8) talked to someone about how they were feeling about the diagnosis and 18.2% (n=6) sought for intervention about the side effects. Only 6.1% (n=2) of those who were extremely affected reported moments of receiving professional help. This indicates that there is a serious need for oncologists and nurses to foster a relationship of care and collaboration with caregivers. Zabalegui, Cabrera, Navarro & Cebria (2013) had similar findings that very few caregivers get professional help, thus confirming the importance of support and counselling for the caregivers [46].

Focus Group Discussion Results Summary

The questions asked during the focus group discussion captured the caregivers' relationship with their patients, their involvement in the diagnosis and treatment, explanation of the effects of the treatment, how they learnt to care for the survivors and the effects of caregiving on their lives.

According to the responses in Table 10 above, 25% (n=5) of the respondents were spouses, 10% (n=2) were brothers, 5% (n=1) was a sister, 10% (n=2) were sons, 10% (n=2) were daughters, 15% (n=3) were mothers, 5% (n=1) was a father and 20% (n=4) were hired and had no blood relationship with the patient. The majority of the caregivers 80% (n=16) were typically from the nuclear family, a finding very similar [47].

In Table 11, when the caregivers were asked about being involved in the diagnosis and treatment of the patients, 45% (n= 9) said yes, 40%

Marital Status	No of people	Percentage
Married	12	60%
Single	6	30%
Divorced	2	10%

Table 4: Marital status of the respondents.

	No. of Respondents	Percentage
Employed	3	15%
Unemployed	17	85%

Table 5: Employment Status.

	Not at all	A little bit	moderately	Quite a bit	Extremely	Total
Feelings of reminder of diagnosis and treatment of colorectal cancer	1	2	2	8	7	20
Sleeplessness	0	2	7	6	4	19
Thoughts related to diagnosis and treatment	1	1	2	5	11	20
Reflection thoughts	2	1	2	8	7	20
Pictures about the cancer	1	1	1	8	9	20
Reflection about what happened during diagnosis	1	3	1	6	9	20
Waves of strong feeling about diagnosis	1	2	4	7	6	20
Dreams about diagnosis and treatment.	3	3	4	5	5	20
Avoided getting upset	1	1	3	8	7	20
Feeling like it wasn't real.	2	1	5	5	7	20
Total	13	17	31	66	72	199

Table 6: Stress Reactions on Intrusion of Thoughts Scale.

	Not at all	A little bit	moderately	Quite a bit	Extremely	Total
Felt irritable and angry	1	1	1	4	13	20
Was jumpy and startled	2	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
Was watchful and on guard	0	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
Was aware had feelings about it	1	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 after 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 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 after 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.

Effects of Care	No.
Stigmatization	12
Burnouts	11
Exhaustion	8
Financial Struggles	12
Fear	8

Table 14: Effects of care on caregivers.

Table 14 above demonstrates the respondents' answers to the effects of the caregiving process in which they explained their pain and suffering which was analysed and categorized under the following themes: 21.6% (n=11) experienced burnout; 23.5% (n=12) were stigmatized; 15.7% (n=8) experienced exhaustion; 23.5% (n=12) experienced financial struggles and 15.7% (n=8) experienced fear. This demonstrates that family caregivers' counselling needs are multifaceted: social (stigmatization), physical (burnouts and exhaustion), financial (financial struggles) and emotional (fear). In the absence of psychological support from the healthcare providers, the caregivers develop coping strategies which are not effective. Adelman et al. (2014) in their clinical review of Caregivers' Burden affirm these findings and recommendation for counselling and support for family caregivers [47].

Conclusion

A colorectal cancer diagnosis or disfigurement of the appearance of the survivor was a source of stress to the caregivers. Due to ineffective coping skills, the caregivers demonstrated high levels of stress reactions. The caregivers sought to avoid the feelings they had towards the survivor they were taking care of. They also sought to stay away from the reminders of the diagnosis and treatment; they did not deal with their real feelings; they felt numb about the very feelings and tried not to talk about them.

Structured education and support at the time of diagnosis and involvement in the treatment plan were identified as a key counselling need for caregivers to enable them deal with the crisis of a cancer diagnosis. Incorporating counselling for caregivers in the treatment

plan will ensure that they are supported throughout the treatment continuum and understand the purpose of various tests and outcomes. The counselling needs of the caregivers should be met alongside those of the patient both in joint and separate sessions to ensure better treatment and management outcomes.

Counselling based on the cognitive behavioural family therapy will help caregivers to be well prepared to accept the colorectal cancer situation their patient is facing and be able to take care of themselves and the survivor better. In addition, the cognitive behavioural family therapy will prepare caregivers to deal with hyper-arousal of thoughts by making them aware of the effects of the realities accompanying the treatment and care of their patients. Being better prepared to deal with strong feelings will help maintain emotional stability and avoid triggering certain stress reactions.

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