

ORIGINAL ARTICLE

Qualitative Insights on the Caregiving of Gastrointestinal Cancer Patients with Low Quality of Life Scores

Nik Nairan Abdullah¹, Hamidah Yamat², Idayu Badilla Idris³, Nik Muhd. Aslan Abdullah⁴

¹ Department of Public Health Medicine, Faculty of Medicine, Universiti Teknologi MARA, 47000 Sungai Buloh, Selangor, Malaysia.

² Faculty of Education, Jalan Temuan, Universiti Kebangsaan Malaysia, 43600 Bangi, Selangor, Malaysia.

³ Department of Community Health, Faculty of Medicine, Universiti Kebangsaan Malaysia, Jalan Yaacob Latif, Bandar Tun Razak, 56000 Cheras, Malaysia.

⁴ Oncology Clinic, Sunway Medical Centre, 47500 Petaling Jaya, Selangor, Malaysia.

ABSTRACT

Introduction: Caring for gastrointestinal cancer patients can be demanding and to some, caregivers, burdensome; resulting in them having low quality of life (QOL) and thus they may become the next potential patients. Hence, true heartfelt experiences need to be captured to highlight issues and preventive measures that are not voiced out as most often caregiving is done in silence and out of responsibility. Therefore, this study aimed to explore on the caregivers' insights on how caregiving experience has resulted in their low QOL. **Methods:** Seven family caregivers were purposively selected from two oncology centres in the Klang Valley, Malaysia for this qualitative case study. The selection was based on the low scores obtained from Malay Caregiver Quality of Life Cancer (MCQOL) questionnaire during an initial cross-sectional study. Following that, in-depth interviews were performed on those selected caregivers. Interview data were triangulated with the questionnaire and observations for validity. Member and expert checking were conducted to ensure credibility and trustworthiness. A thematic content analysis was later performed. **Results:** Thematic analysis revealed four distinct contributors to the caregivers' QOL; namely, patients' financial and stress management; impact towards physical, psychological, social (including relationship) wellbeing, communication; and support from families, organisation and community. **Conclusion:** The qualitative study discovered evidence for collaborative support needed to ensure better QOL for the caregivers.

Malaysian Journal of Medicine and Health Sciences (2023) 19(1):140-148. doi:10.47836/mjmhs19.1.20

Keywords: Caregiving, Gastrointestinal cancer, Qualitative, Family caregivers, Quality of life

Corresponding Author:

Nik Nairan Abdullah, PhD

Email: niknairan@gmail.com

Tel: +60 3-61265000

INTRODUCTION

The increasing number of gastrointestinal (GI) cancer patients in Malaysia, commonly due to colorectal cancers has resulted in a growing number of informal caregivers; most often, family caregivers. Due to the familial relationship, family caregivers are regarded as primary caregivers to cancer patients who provide uncompensated care and health-related assistance (1). Caregivers have a huge responsibility, and this may also change from time to time according to the patients' conditions before and after treatment. This is due to the fact that cancer is a dynamic and chronic illness.

Family caregivers may also have social responsibility conflicts, marriage issues, familial relationships, limited daily activities as well as other emotional and health issues (2). Studies have shown that caregiving of

cancer patients will affect their health-related QOL and subsequently impact the caring of these cancer patients (3).

Furthermore, with advanced medical treatment, cancer patients have longer survival periods which then result in longer need for caregiving. The care for GI patients poses even greater challenge because of poor diagnosis resulting in a delayed detection and a need for a higher level of patient care (4). Therefore, it is imperative to ensure that family caregivers have high QOL so that they can perform their caregiving responsibility effectively thus preventing them from becoming potential patients. Quality of life (QOL) as defined by the World Health Organization (WHO) is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (5 p. 1405). It is a broad concept that encompasses physical health, psychological health, personal beliefs, social relationship and environmental features. It is a subjective measurement for both positive and negative aspects of

life (6).

Local studies showed that cancer caregivers have lower QOL in comparison to the general population (7). The QOL of cancer caregivers in Singapore and other Asian countries was documented to be lower than those in Western countries (8). Meanwhile, there is a relationship between patients and their caregivers' wellbeing i.e if the caregivers' health is affected, so do the patients' (9, 10). In addition, cancer patients' spouses are more at risk of health conditions where a study shown an increase of 13% of heart attack cases and 26% of stroke cases among family caregivers with more than 10 years of caregiving (11).

Often, past studies have employed standardized quantified instrument to determine the QOL. Despite the informative findings from quantitative data, they lack meanings as the voices of these individuals were seldom heard to explain the challenges faced and how they managed the task and perhaps at the same time, reveal the support needed to help them improve their QOL. A qualitative research approach enables insights to be gathered and thus able to provide explanations of a phenomenon. In relation to the context of the study discussed in this article, insights on cultural variation, societal expectation, and beliefs, for instance, can be captured through in-depth interviews and observations (12). Qualitative findings from caregivers' perspective will add to existing knowledge on caregiving. In addition, studies that explore a sub-group with low QOL are limited. These sub-groups should not be disregarded or neglected as they may subsequently suffer in silence.

In addition, this study focuses on gastrointestinal (GI) cancers due to the increasing number of this cancer in Malaysia as well as in other parts of the world. Upper GI cancers are associated with poor mortality whereas lower GI cancers have better prognosis. Moreover, life expectancy for lower GI is longer due to the advancement of treatment. Consequently, longer caregiving is required. Furthermore, there was still a lack of studies on caregiving of specific cancer types (13). Therefore, this study aimed to explore on the caregivers' insights on how caregiving experience has resulted in their low QOL.

MATERIALS AND METHODS

A qualitative study using a case study approach was conducted the oncology units located in two major referral hospitals in Klang Valley. This study was merely to gather the participants' insights on their caregiving experiences and not intended to gather any emerging theory.

The findings reported in this study are a part of a larger study which also involved a quantitative method with the purpose to measure the caregivers' QOL. This

was needed to help determine the participants for the qualitative study.

The initial part of the study measured QOL of the GI cancer caregivers using the Malay Caregiver Quality of Life (MCQOL) instrument. Caregivers were identified by the gastrointestinal cancer patients at the oncology units. Data was collected via interview at designated rooms. MCQOL is an instrument that has a good psychometric properties to assess the QOL of cancer caregivers and was found to be reliable in the local population (14). There are 35 items categorized into five domains which were burden= 10 items, disruptiveness=7 items, positive adaptation=7 items, financial concerns=3 items and other factors (sleep disturbance, satisfaction with sexual functioning, day-to-day focus, mental strain, being informed about the illness, protection of the patient, management of the patient's pain, and family interest in caregiving)= 8 items. Each item had a likert scale of 5 (0 to 4). Higher scores denotes lower QOL. The reliability of the MCQOL was good, with a Cronbach's alpha of 0.90. (15).

From the MCQOL analysis, respondents with low QOL scores were identified for the qualitative study. In selecting the participants for the study, a purposive sampling technique was carried out. Besides having low QOL scores, seven respondents also fulfilled other inclusion criteria such as they belong to any of the major ethnicities such as Malay, Chinese and Indian; were unpaid caregiver; third, had a kin/close relationship with the patient (spouse, children, relative, or close friend; were Malaysian or permanent resident; aged above 18 years old; sixth, able to communicate and understand the Malay or English language; and finally were willing to engaged in the in-depth interview. Seven respondents fulfilled the above criteria. No new recruitment was carried out when the data has reached saturation.

Data collection

The caregivers were contacted via telephone, email or short message service. The researcher informed the respondents of their QOL score and that they are invited for the in-depth interview. Appointments were made to meet the caregivers during the patient's visit to the hospital. Written consents were also taken after the caregivers were given a briefing on the conduct of the study.

Meanwhile, the in-depth interviews (IDI) with the caregivers were conducted in a designated room in the clinic to ensure their comfort. The interviews were conducted based on a semi-structured interview protocol (Table I) adapted from previous study (16). In addition, field notes were taken during the interview to include observations of the non-verbal cues such as facial expression and body gestures. After every interview, the caregivers were given a chance to ask questions to clarify what they have said. They were also

Table I: Interview Protocol

Respondent characteristics		
Date		
Time		
Location of interview		
Relationship type with patient		
Age, ethnicity, patient's cancer type		
Main questions	Sub-questions	Probing questions
How do you feel when you knew the patient had cancer?		What were your reactions?
How did you care for the patient?		What activities do you do?
Can you tell me the hardship while caring for the patient?		What problems did you encounter?
How caregiving affected your daily life?	Physical health Psychological health Financial Social life	
How did you face the problems during caregiving?		What did you do when you face problems?
How was the support from other people for the caregiving?		Support from family members and friends?
How was the support from others?		Organization? Non-government bodies? Community?
Have I explored all aspects of caregiving?		Are there any other issues on caregiving that you will like to tell?

asked for their consent for the subsequent interview for clarification if needed and for member checking. Each IDI took between 45-50 minutes. The audio-recording of the IDIs were verbatim transcribed. A total of seven eligible caregivers completed the IDI until saturation point has been achieved.

The caregivers were assured that the audio-taped interviews would be kept confidential, and their actual names would not be revealed in the reporting of the study by using pseudonyms.

Permission to conduct the study was obtained from the ethics committee of the National University of Malaysia, UKM PPI/111/8/JEP-2017-433 and the Medical Research and Ethics Committee, Ministry of Health Malaysia, NMRR ID:17-898-35896. The qualitative data collections were carried out for six months from October 2017 to March 2018.

Data analysis

The audio-recording were transcribed by the researcher. Only one session of IDI was conducted in a day so that there was time for transcribing. The transcribing of one transcript took an average of three to five hours to complete. Transcriptions were coded using Atlas.

ti software. A thematic content analysis was conducted for data analysis. Themes were both pre-determined based on literature as well as developed from the data. We performed coding as an initial step for a detailed analysis and provided the outcome for a report (17). Similarities between the first coding were categorized into sub-themes. The same process was applied to the theme's categorization.

Trustworthiness of the data is the degree of confidence in data interpretation and methods used to ensure the quality of this study where rigorousness of triangulation of data; that is the "convergence of multiple and different sources of information to form themes or categories in a study" - the in-depth interviews, observations and QOL questionnaire (18). Themes were then validated through expert checking where three experts in the field - a palliative nurse, an oncologist, and a clinical psychologist verified the themes developed from the verbatim transcriptions. Throughout the in-depth interview, the non-verbal aspects such as body language and facial expression were documented, and these were integrated with the caregivers' verbatim.

RESULTS

Table II shows the profile of the respondents. The respondents' age ranged from 22 to 64. All caregivers were spouses to the patients except two who were daughters and one was a sister to the patients. All cancer patients were at stage four. The duration of care was from two months to three years. The range of the mean scores of their QOL was from 33 to 57. The lowest QOL score was 33 from V, a 42-year old lady caring for her father, an esophagus cancer patient. Meanwhile, the highest QOL score was 57 from I, a 22-year old university student caring for her father.

The breakdown of the MCQOL scores for each participants are also shown in Table II where the domains are arranged according to the most to least affecting. In other words, the themes from the qualitative data are evidence of the scores. Most respondents reported highest score (lowest QOL) in the burden, disruptiveness and other factors domains. According to the respondents' background, relationship to the patients such as being a daughter or sister, gave other factors as one of the predominant domains that was greatly affected by the caregiving.

Meanwhile, eleven sub-themes were derived, which were then categorized under three main themes; i.e management, impact and support. Table II indicates the themes and sub-themes. The subsequent sections illustrate the caregivers' responses from which the themes were derived.

Management

Three sub themes were categorized under management.

Table II: Qualitative Respondents' Information

No.	Caregiver description (Initials, age in years old)	Patient's cancer type	Relationship with patient	QOL score	Score for Domains of QOL
1.	B,64	Pancreas	Husband	42	Burden=28 Disruptive-ness=25 Other factors=25 Positive adaptation=9 Financial=1
2.	I,22	Oesophagus	Daughter	57	Burden=33 Other factors=20 Positive adaptation=15 Disruptive-ness=12 Financial=9
3.	A,32	Colon	Wife	52	Burden=25 Disruptive-ness=16 Other factors=22 Financial=5 Positive adaptation=3
4.	C,51	Rectal	Sister	44	Other factors=31 Burden=28 Disruptive-ness=18 Positive adaptation=4 Financial=3
5.	V,42	Oesophagus	Daughter	33	Burden=23 Other factors=17 Disruptive-ness=16 Financial=8 Positive adaptation=2
6.	N,63	Colon	Wife	40	Burden=34 Other factors=23 Disruptive-ness=20 Positive adaptation=1 Financial=0
7.	S,36	Colon	Wife	42	Burden=32 Disruptive-ness=21 Other factors=16 Positive adaptation=7 Financial=6

*The higher the scores, the lower the QOL. For positive adaptation, the higher the score, the less adaptation, and the lower the QOL.

Table III: Themes and Sub-Themes

Sub-themes	Themes
Managing patient Financial Stress	Management
Physical health Psychological health Social life Relationship Communication	Impact
Family Paid assistance Community	Support

The findings indicated that the caregivers had to manage the patient, financial matters and stress. First, most of the caregivers highlighted that they spent most of their time managing the dietary habits of the patients. According to Caregiver N:63, her spouse (patient) *“lacks appetite ... less eating can't smell rice ... [and] after eating ... vomits, a lot”*. This shows that the gastrointestinal symptoms were prevalent such as lack of appetite and food intolerance. As a result, the caregivers *“tried to google... learn and read what fruits can be eaten [to] ...see if there is any food that [she] can give [her husband - the patient] strength. [She therefore] read a lot of article...”* (Caregiver S:36). She spent her time seeking nutritional information for cancer illness and giving advice to the patient on food intake.

Managing pain is another concern. Caregiver N:63 described having to manage the pain her husband was feeling. In despair she said, *“when he gets worse, in pain...I could only rub his back, that's all I can do...”*. Meanwhile, Caregiver B:64 who is the husband to a pancreatic cancer patient described having to manage the side-effects of his wife's treatment which were weight loss, lethargy, and amnesia. According to him, *‘...when about to do second stage chemo, her (patient) strength lessen... her body weight drop a lot... before that she was 90 now until 60... she eats less...’*.

Second, the caregivers had to manage the finance as the patients could no longer work which resulted in loss of income for the family. Caregiver I, a 22 years old daughter had to struggle financially and live on savings that was running low. Since her *“dad ... can't work ... so salary is less... so [they] depend on mom's salary which is not much and mum's salary is for cab fare and medical board also can't last long...”* Similarly, Caregiver S, aged 36, the wife of a colon cancer patient described experiencing financial constraint. Eventhough they own a house, she still has to keep *“paying monthly... car still paying ... children expenses ... transport, tuition all from [her] salary. So much so that she had to “teach [her children] to have rice [for] lunch then night eat bread ...”*

Third, the caregivers had to manage their stress by performing practices related to religion or faith. For Caregiver B:64, he felt that he had to manage his time for prayers while caregiving. For him, when he prays, he *“feel[s] a bit cool ... [because] when we pray, we are close to God ... if don't pray, we make do”*. According to him, *“that's all we can afford to do.”* Caregiver N:63 too said that she prays and does *“a lot of reading the Qoran.”* According to her, *she can only complain to Allah (God) as other people cannot help [her]*. When she does complain to others, they will just say their sympathy and ask her to be patient. Caregiver I:22 too indicated managing the patient involved her faith or religion when she admitted that although the caregiving is a huge burden, she said that *“this is responsibility...”*

that everything happens has hikmah(blessing) ... that Allah(God) has 'something' for her" or that she will be rewarded in her later life. Similarly, Caregiver A:32, the wife of a colon cancer patient expressed her consent to the fate she received. She said '... redha (consent)... [because it is her] husband... it is like our responsibility so patience....just patience...'

Impact

The second category of theme is impact of caregiving on the caregivers' physical health, psychological health, social life, relationship, and communication. These were five sub-themes which were derived. First, the impact on the caregivers' physical health. Caregiver B:64 said that he suffered hypertension. Prior to his wife's illness, he had *"no high blood pressure now got high blood a bit...well ... taking care of patient"*. However, for some caregivers, getting medical attention was a challenge. Caregiver N:63 expressed her intention to get treatment from the doctor for her health condition. Due to the excessive use of her upper limbs to carry the mattress for the patient, she was diagnosed with Carpel Tunnel syndrome. Unfortunately, she did not seek regular medical attention because she felt guilty of leaving her sick husband alone at home. According to her, *"the doctor said every month [she] had to do physio with [her] hand, because [she] has numbness of hands. However, when she wanted "to get treatment ... a lot of people [said]... how to leave [her] husband alone at home... [so] what ever happens, [she] [did not] have the heart to leave him alone"*. Meanwhile, Caregiver S:36 complained of irregular periods and frequent body ache. She said, *"my period irregular...I feel pain very often...I have headache."* However, she showed lack of health-seeking behaviour such as seeking medical attention. She also admitted that she *"did not take medication, didn't see doctor"*. She however resorted to traditional herbal as she said that she *"took traditional like ginger for pain killer"*.

Psychological health was the second impact of caregiving. Caregiver B:64, a male spouse looking after his pancreatic cancer wife admitted that he *"feel[s] angry sometimes"*. However, he continued saying *"... what can I do, this is my responsibility as a husband it is my duty to care for her...that's all"*. This reflects the dilemma he faced which may result in a psychological impact. He too had to convey bad news about his wife to his family members. He felt *"let [him] be the only one who knows...because [he] can't see [his] children sad ... and when it comes to a point... [he should] say mama is having cancer stage 4...but [he tells] them, stage 2 and can treat it...but just a lie..."*. Meanwhile, Caregiver C also confessed that *"...[she] fears for him, if there is anything ...scared.. ...I am very stress taking care him ..."*

The third impact is on the caregivers' social life. For instance, Caregiver N:63 expressed that she missed going for religious activities with her husband as she

recalled the time spent together with him. She said *"I will go together to mosque with pakcik (patient) ...listen to talk...haa... that is what is missing...a lot...Until now, I feel "God, when can you give back that chance to me"*. This implies her missing the social activities that she normally does with her husband. Meanwhile Caregiver A:32 could not run her business as usual because *"everything [she] had to do on [her] own ... so like a lot of things out of schedule ... it disrupts a lot"*.

The fourth impact is related to the intimate relationship between the patient and the caregiver. For instance, Caregiver N:63 felt that she had lost her soul mate. For her, *"with him only us in this world. Kids they help but ...the intimacy. It's not the same with the kids. Our care and concern towards our husband is not the same with our children"*. Similarly, Caregiver A:32 admitted that *"the affection is less...less...it's difficult to explain... previously, we were close...after that...like...his treatment not the same... he is just lying there..."*. It was difficult for these caregivers to express their frustration especially in the Asian culture, such discussion may be seen as a taboo. Yet, they indicated this as the impact of caregiving.

The fifth impact is related to communication. In caregiving, there would be a substantial amount of communication between the caregivers and the hospital staff; particularly during the medication process and procedures. This is where the communication theme appeared when one of the caregivers (Caregiver N:63) expressed the difficulty she has to face in communicating with a hospice worker. She said that *"the problem with me was that I don't know English, she (hospice worker) could not speak Bahasa (Malay language). It became duck and chicken talking...So he (patient) helped me translate..."*. This somehow created a difficult situation for her which added to her stress in caregiving.

Support

The third category of theme is support (sub themes - family, paid assistance, community) which include the support that they give in caregiving as well as the support they received. For Caregiver A:32, she seems to be the only support that her husband wanted. Although her husband had his family nearby including his parents, *"he just wants me...all husbands like that right...he wants his wife still, no one else"*. Meanwhile, Caregiver B:64 refused to hire an outsider to look after his wife because he did not trust an external help. According to him, he *"can manage it..on my own, you know when other people care, it is just for money, my experience taking care my mom, mom took a carer, she took care for money"*. His experience with looking after his mother taught him not to trust others. However, Caregiver N:63 received moral and spiritual support from the committee of a nearby mosque. She said, *"the mosque committee ... came to visit... to see, how is the condition...[and] there was one time, at the hospital, they came [and]*

recite surah (verses)". Although there was no monetary support, this was seen by Caregiver N:63 as a moral support.

DISCUSSION

These findings indicate that family caregiving of patients with chronic and fatal diseases such as cancer would result in poor QOL. When the caregivers were not properly trained and often unprepared, they had to endure their lack of knowledge. These caregivers had to manage the patients' gastrointestinal system such as pain and change in dietary habits. This includes the numbness and tingling sensation of proximities were felt among colorectal patients who undergo chemotherapy (19). Lack of knowledge on managing symptoms pertaining to gastrointestinal organs including the side-effects of chemotherapy as well as on dietary needs of the patients all of which posed challenges to caregivers. Financial burden too is common in cancer caregiving (20). As our findings pointed out the unmet needs of the caregivers while fulfilling the needs of the patients, there was a need to create a balance between the patients' and the caregivers' needs. For example, arrangement could be made to release some of the 'burden' faced by the caregivers; or moral and physical support could also be given to these caregivers. In balancing the leisure activities with long-term care, the advice from visiting nurses is vital (21).

Religion has a fundamental influence on the acceptance of cancer diagnosis (22); indicating that faith is fundamental in preparing oneself for tasks and even in difficult situations. The acceptance of cancer diagnosis and current situation (23) including increasing spiritual activities (24) were their coping mechanisms. For instance, the word Redha (acceptance) was usually uttered as indicated in the conversation "She wholeheartedly accepts the death of her son. Life must go on" (25). The caregivers also resorted to faith to reduce their depression level (26). Spirituality is thus important because it can be one of the predictors to the health status of caregivers and readiness for caregiving (27).

Culture ways is another coping mechanism as the concept of filial piety in Eastern society is a norm where it is rewarding for children of all ages to care for their parents (28). The caregivers uphold responsibilities to care for patients because of two reasons which were to fulfil the society's needs as well as practical needs when there no suitable caregiver available (29). A strong family relationship functions as a protection against the negative outcome and increases the positive outlook from caregiving (30). Caring for the spouse was also perceived as an honourable responsibility with a reward in the afterlife. This coincides with our finding (24). Non-Caucasian caregivers held strongly to the filial piety and inclined to use religion as a coping mechanism for stress

(31). Hence, these findings corroborate with the idea that the surrounding Asian community embraces religion and culture. These two factors played a vital role in coping with the psychological impact of caregiving when life changes that took place. Similarly, the caregivers in our study seem to uphold strongly to faith that may have helped them to accept the initial diagnosis of cancer.

Patients' diagnosis and treatment interfered with the social life of the caregivers (32). Sexual intimacy worsens when one of the spouses was terminally ill. Discussing sex and demanding sexual intimacy from the patient were seen as inappropriate in this cultural context. In the Asian culture, open discussion on sex has always been considered a taboo. The lack of human physiological needs could eventually lead to depression and anxiety among the caregivers. There have been reports on alteration of sexual life, the sexual activity stopped, including no energy for sexual activities (re-evaluation of relationship) (33). Apart from that, social activities, such as attending religious classes, performing prayers at the mosque, had been found to be important to the spiritual wellbeing of the caregivers. Disruption to these religious community activities cause profound sadness.

Community support in the Malaysian culture regarding cancer caregiving was not highlighted in previous literature. The caregivers received the most support from close family members and friends. Community support as perceived by the caregivers in this study was limited to religious activities with no involvement of financial aid. On the other hand, the African American caregivers expressed the lack of community support groups and church support in their community. Health promotion activities can utilize religious centers to connect cancer survivors and caregivers (34). Perhaps also, a form of community support or caregivers' support group could also be provided. Studies have shown that psychosocial support systems can lead to improved outcomes among cancer survivors (35).

In addition, communication breakdown due to the language barrier was reported between the caregiver and the health provider. Therefore, health providers must be vigilant towards the language needs of the caregivers and understand the needs to provide support for the communication difficulties (36). This is because a good communication influence positively towards the caregiver's QOL (37).

The findings of this study imply the need for providing various forms of support to caregivers. These includes support for knowledge on the illness as well as caring for the patients' needs such as dietary practices; support on how to handle the patients, the need to have adequate training; financial support; and finally moral support. Furthermore, the caregivers expressed poor health-seeking behaviour due to the demand of the caregiving.

This health impact should be taken into consideration when assessing the caregivers' wellbeing.

Future direction should strengthen the healthcare services beyond the treatment of the cancer patients only. Health care providers have a major role in creating accessibility to mental health services and respite care for the caregivers. Health care personnel should also be attentive towards the problems of caregiving and emotions that the caregivers display. Listening to their problems and giving advice, when necessary, would be useful for the caregivers. There is a need to empower these caregivers who suffer in silence and at the same time help them to increase their health literacy and coping skills. Health literacy includes conveying cancer information and advocates healthy seeking behaviour to prevent the occurrence of physical and psychological morbidity among the caregivers. The oncology unit can employ trained counsellors in their units since the cancer trajectory is an unpredictable journey. Routine distress screening and referral system are beneficial for caregivers who showed a sign of distress.

This study has illustrated the strength of a qualitative study that not only to prove but explains a phenomenon. Existing quantitative instruments determine their QOL while qualitative instrument provide the hidden views and voices of the caregivers that highlight the challenges and difficulties they have experienced and the need for help or support. However, there are some limitations. There is selection bias when recruiting the respondents. The caregivers who were identified by the patients may not be the primary caregivers such as spouses who were at home and not accompanying the patients to the hospital.

The findings of this qualitative study differ from other types of cancer burden as the gap of this study was to gain insight on cultural and societal aspects of caregiving. Hence the findings have provided added insights if not totally new on the caregiving of GI cancers in comparison to other types of cancer. The new findings gathered were lack of support from the healthcare providers regarding management of patients, communication breakdown with healthcare providers, community support and poor health-seeking behaviour of the caregivers. There were no cultural variation seen among respondents who comprised of major ethnicities. This is because the culture of caregiving revolves around 'filial piety' - a virtue of respect for one's parents, elders, and ancestors (38).

CONCLUSION

The domains of QOL that were greatly affected were burden, disruptiveness, and other factors, among the caregivers with low QOL. The qualitative findings revealed how caregiving of gastrointestinal cancer patients resulted in the low QOL. Furthermore, the

qualitative study also found some emerging factors such as support from healthcare providers, organisation/ community, and caregivers' health-seeking behaviour.

ACKNOWLEDGEMENTS

Acknowledgement are addressed to the health personnel of the Ministry of Health and the National University of Malaysia Medical Centre in assisting in the process of data collection; the Director General of Health Malaysia for his permission to publish this article; Faculty of Education, UKM for the GG2019-016 Dana Penyelidikan Fpend fund for funding this study.

REFERENCES

1. Padmaja G, Vanlalhruii C, Rana S, Tiamongla & Kopparty S. Quality of life of patients with cancer: a determinant of the quality of life of their family caregivers. *J Cancer Educ.* 2016;1-7. doi:10.1007/s13187-016-1000-y.
2. Given BA, Given CW & Kozachik S. Family support in advanced cancer. *CA: A Cancer Journal for Clinicians.* 2001;51(4): 213-231. doi:10.3322/canjclin.51.4.213
3. Salonen P, Rantanen A, Kellokumpu-Lehtinen PL, Huhtala H. & Kaunonen M. The quality of life and social support in significant others of patients with breast cancer—a longitudinal study. *European Journal of Cancer Care.* 2014;23(2): 274-283. doi:10.1111/ecc.12153
4. Shaw J, Harrison J, Young J, Butow P, Sandroussi C, Martin D. et al. Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Support Care Cancer.* 2013;21(3): 749-756. doi:10.1007/s00520-012-1575-8
5. WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine.* 1995;41(10):1403– 1409. doi:10.1016/0277-9536(95)00112-K
6. WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties. *Soc Sci Med.* 1998;46:1569-1585. doi: 10.1016/s0277-9536(98)00009-4
7. Che Bakar O, Yusoff EH, Anisah Omar A. Psychiatric morbidity and quality of life among family caregivers of hospice patients with cancer: a home based community preliminary study. *ASEAN Journal of Psychiatry.* 2008 [cited 2019 Dec 15]: 9(2):78-84. Available from: https://myjurnal.mohe.gov.my/filebank/published_article/15386/AJP_2008_Osman.pdf
8. Lim HA, Tan JYS, Chua J, Yoong RKL, Lim SE, Kua EH et al. Quality of life of family caregivers of cancer patients in Singapore and globally.

- Singapore Medical Journal. 2016;1:1–13. doi: 10.11622/smedj.2016083
9. Kent EE, Rowland JH, Northouse L, Litzelman K, Chou WS, Shelburne N et al. Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*. 2016;122(13):1987-1995. doi:10.1002/cncr.29939
 10. Abdullah NN, Idris I, Shamsuddin K & Abdullah Nik. Health-related quality of life in Malaysian gastrointestinal cancer patients and their family caregivers—a comparison study. *Supportive Care in Cancer*. 2020; 28(4):1891-1899. doi:10.1007/s00520-019-05007-5
 11. Ji J, Zoller B, Sundquist K, Sundquist J. Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients. *Circulation*. 2012; 125:1742-1747. doi:10.1161/CIRCULATIONAHA.111.057018
 12. Creswell JW and Piano Clark VL. *Choosing a mixed methods design*. London: SAGE;2011.
 13. Vanlalhruii C, Padmaja G & Kopparty S. Quality of life of elderly cancer patients as predictor of their caregivers' quality of life. *Indian Journal of Gerontology*. 2018[cited 2019 Dec 8]: 32(3): 273-281. Available from <http://www.gerontologyindia.com/pdf/vol-32-3.pdf#page=47>
 14. Lua PL, Norhayati M & Ahmad Kashfi AR. HRQoL profile and psychometric properties assessment of caregiver quality of life instrument among HIV/AIDS family caregivers in Terengganu. *Malaysian Journal of Psychiatry*. 2013 [cited 2018 Jan 13]1:1-4. Available from <http://mjpsychiatry.org/index.php/mjp/article/view/231/173>
 15. Abdullah NN, Idris IB, Shamsuddin K & Abdullah N. Health-Related Quality of Life (HRQOL) of Gastrointestinal Cancer Caregivers: The Impact of Caregiving. *Asian Pacific Journal of Cancer Prevention*. 2019;20(4): 1191–1197. doi:10.31557%2FAPJCP.2019.20.4.1191
 16. Mancini J, Baumstarck-Barrau K, Simeoni MC et al. Quality of life in a heterogeneous sample of caregivers of cancer patients: an in-depth interview study. *European Journal of Cancer Care*. 2011;20(4):483-492. doi:10.1111/j.1365-2354.2010.01227.x
 17. Richards L & Morse JM. *Read me first for a user's guide to qualitative methods.*, California: Thousand Oaks;2002.
 18. Creswell JW & Miller DL. Determining validity in qualitative inquiry. *Theory into Practice*. 2000; 39(3): 124-131. doi:10.1207/s15430421tip3903_2
 19. Ruhl K, Guren MG, Astrup GL, Smestuen MC. & Rustuen T. High symptom burden is associated with impaired quality of life in colorectal cancer patients during chemotherapy: a prospective longitudinal study. *European Journal of Oncology Nursing*. 2020; 44:101679. doi:10.1016/j.ejon.2019.101679
 20. Fitch M & Longo CJ. Exploring the impact of out-of-pocket costs on the quality of life of Canadian cancer patients. *Journal of Psychosocial Oncology*. 2018;1-15. doi:10.1080/07347332.2018.1486937
 21. Omiya T, Kutsumi M & Fukui S. Work, Leisure Time Activities, and Mental Health among Family Caregivers of the Elder People in Japan. *Healthcare*. 2021;9(2):129. doi:10.3390/healthcare9020129.
 22. Alzahrani AS, Alqahtani A, Alhazmi M, Gaafar R, Bajabir D, Alharbi IM. et al. Attitudes of cancer patients and their families toward disclosure of cancer diagnosis in Saudi Arabia: a Middle Eastern population example. *Patient Preference and Adherence*. 2018;12:1659. doi: 10.2147/PPA.S176651
 23. Leonidou C & Giannousi Z. Experiences of caregivers of patient with metastatic cancer: What can we learn from them to better support them? *European Journal Oncology Nursing*. 2018;32:25-32. doi:10.1016/j.ejon.2017.11.002
 24. Kristanti MS, Effendy C, Utarini A, Vernooij-Dassen M & Engels Y . The experience of family caregivers of patients with cancer in an Asian country: A grounded theory approach. *Palliative Medicine*. 2019;33(6): 676–684. doi:10.1177/0269216319833260
 25. MyHealth, Ministry of Health. Surrender or redha. Mental health for prime years [Internet]. Malaysia;2019 [cited 2019 Dec 15]. Available from: <http://www.myhealth.gov.my/en/surrender-or-redha/>
 26. Son KY, Lee CH, Park SM, Lee CH, Oh SI, Oh B. et al. The factors associated with the quality of life of the spouse caregivers of patients with cancer: a cross-sectional study. *Journal of Palliative Medicine*. 2012;15(2): 216-224. doi:10.1089/jpm.2011.0305
 27. Fujinami R, Otis-Green S, Klein L, Sidhu R. & Ferrell B. Quality of life of family caregivers: challenges faced in care of the lung cancer patient. *Clinical Journal of Oncology Nursing*. 2012;16(6):E210-220. doi:10.1188/CJON.E210-E220
 28. Glajchen M. Physical well-being of oncology caregivers: an important quality-of-life domain. *Semin Oncol Nurs*. 2012;28(4): 226-235. doi:10.1016/j.soncn.2012.09.005
 29. Ng HY, Griva K, Lim HA, Tan JY & Mahendran R. The burden of filial piety: a qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychol Health*. 2016;31(11): 1293-1310. doi:10.1080/08870446.2016.1204450
 30. Lai DWL. Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging*. 2010;32(2): 200-223. doi:10.1177/0164027509351475
 31. Juarez G, Branin JJ. & Rosales M. Perceptions of QOL among caregivers of Mexican ancestry of adults with advanced cancer. *Qual Life Res*. 2015;24(7): 1729-1740. doi:10.1007/s11136-014-

- 0911-5
32. Van Roij J, Brom L, Youssef-El Soud M, van de Poll-Franse L and Raijmakers NJ. Social consequences of advanced cancer in patients and their informal caregivers: a qualitative study. *Supportive Care in Cancer*. 2019;27(4):1187-1195. doi:10.1007/s00520-018-4437-1
 33. Ekholm K, Gronberg C, Borjeson S & Bertero C. The next of kin experiences of symptoms and distress among patients with colorectal cancer: diagnosis and treatment affecting the life situation. *Eur J Oncol Nurs*. 2013;17(2): 125-130. doi:10.1016/j.ejon.2012.05.003
 34. Haynes-Maslow L, Allicock M. and Johnson LS. Cancer support needs for African American breast cancer survivors and caregivers. *Journal of Cancer Education*. 2016; 31(1):166-171. doi:10.1007/s13187-015-0832-1
 35. Ashing-Giwa KT. Quality of life and psychosocial outcomes in long-term survivors of breast cancer. *J Psychosoc Oncol*. 2000;17:47– 62. doi:10.1300/J077v17n03_03
 36. Washington K.T, Oliver DP, Benson JJ, Rolbiecki AJ, Jorgensen, LA, Cruz-Olivern DM et al. Factors Influencing Engagement in an Online Support Group for Family Caregivers of Individuals with Advanced Cancer. *Journal of Psychosocial Oncology*. 2019; 1-16. doi:10.1080/07347332.2019.1624674
 37. Wittenberg E, Kerr AM, Goldsmith J. Exploring Family Caregiver Communication Difficulties and Caregiver Quality of Life and Anxiety. *American Journal of Hospice and Palliative Medicine*. 2021;38(2):147-153. doi:10.1177/1049909120935371
 38. Kaur R. Cultural beliefs, cancer and stigma: Experiences of patients from Punjab (India). *Studies on Ethno-Medicine*. 2015; 9(2): 247-254. doi:10.1080/09735070.2015.11905442