

Profiles and types of social support among Cancer Patient

Caregivers

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Abstract

Cancer not only impacts patients but their caregivers too. The objective of this study was to examine the types of social support needed by cancer patient caregivers and to analyse their perception of the importance of social support based on selected demographic factors (age, gender, ethnicity education level, duration of care and income). The data were collected through a survey method, questionnaires were distributed among primary caregivers of cancer patients from the northern states of Malaysia. The findings showed that social support such as emotional, physical and spirituality necessary to help improve the well-being and quality of life of cancer patient caregivers.

Keywords: cancer, psychosocial, social support, well-being, quality of life

Introduction

Cancer is a threat to the health of persons in every age group in Malaysia. It is estimated that 90,000 to 100,000 Malaysians are suffering from cancer. The highest incidence of cancer is among the Malays (4,058 males and 4,753 females), followed by the Chinese (4,078 males and 4,422 females), and Indians (629 males and 1065 females). The records of the National Cancer Registry show that 21,773 Malaysians have been diagnosed with cancer, and it is believed that 10,000 unregistered cases are still occurring annually (National Cancer Society Malaysia (NCSM), 2010). People from every age group, regardless of whether they are children, adults or the elderly, are at risk of cancer. Cancer not only has an impact of health but also results in psychosocial problems, including social, economic and psychological relationships. The impact is not only felt by the patient but also by the whole family, who is involved in each cancer phase.

Studies have shown that cancer is more dominant among women than men at a ratio of 1:12. Meanwhile, the most common types of cancer among Malaysians are breast, intestinal, lungs and cervical cancer (National Cancer Society Malaysia (NCSM), 2010). Breast cancer is the fastest spreading cancer in the world. Statistics

show that 23% of the 12.7 million cases of cancer reported are breast cancer cases (Kassim, Hanafiah, Cheung & Rahman, 2015; Loh, Packer, Yip & Low, 2009; Loh, Chew, Lee, Quek, 2011; Yip, Taib & Mohamed, 2006). Chinese and Indian women are more likely to have breast cancer than Malay women. What is even sadder is that breast cancer is the leading contributor to cancer deaths among women in Malaysia (Taib, Yip, Ibrahim, Ng & Farizah, 2007). Although cancer is generally known as a disease that affects the health of patients, the effects of cancer on the immediate family members are still unknown. Studies in relation to cancer in Malaysia have been focusing more on the medical aspects and are clinical in nature, especially on cancer prevention, early detection of cancer, early treatment of cancer, general education about cancer and a healthy lifestyle to prevent cancer. However, less attention has been given to the psychosocial aspects of what happens to the cancer patients and their caregivers as well as their immediate family members. In addition, the roles and problems faced by caregivers have also been ignored in previous studies.

Chronic patients, including cancer patients, are defined as individuals with long-term physiological, mental and/or physical disabilities, who require constant care and monitoring. It is usually difficult for chronic patients to recover in a short period of time. At the same time, this has a long-term impact on caregivers and families physically, economically, emotionally as well as on their level of health (Nur Saadah Mohamad Aun, 2012; Trudeau-Hern & Daneshpour, 2012).

Cancer not only affects the health of the patient but also involves other psychosocial problems including social, economic and psychological relationships (Lund, Ross, Petersen, & Groenvold, 2014). It impacts not only the patient but also those who present in each phase of the cancer, whether as a caregiver or as a family member of the cancer patient (Reblin, Donaldson, Ellington, Mooney, Caserta, Lund, 2015). These care activities involve a series of social relationships between the caregiver and the patient (such as the relationship between a husband and wife, the relationship between a child and the mother or father who is being cared for, as well as the relationship between siblings) (Nur Saadah Mohamad Aun, 2012). In the Malaysian context, the family members are the primary caregivers in the care of those who are critically ill such as with cancer.

The task of caring for cancer patients is not only focused on helping the cancer patient to move or merely administering medications. Cancer patients sometimes need words of encouragement from their caregivers. Other than the cancer patients, their caregivers also need to hear words of encouragement from individuals or

others. Thus, sharing in the form of support groups will help caregivers gain new strength in caring for cancer patients (Sklenarova, Krümpelmann, Haun, Friederich, Huber, Thomas, 2015). Previous studies have shown that the well-being of caregivers plays a very important role in helping patients throughout their course of treatment and recovery. Caregivers who receive good social support will be able to establish better and stronger relationships with patients (Griffin, Meis, MacDonald, Greer, Jensen, Rutks & Wilt, 2014; Pasek, Dębska & Wojtyna, 2017). Caregivers of cancer patients desperately need the support of the people around them to give them that resilience and to enable them to restructure their needs in life both financially and socially (Shilling, Starkings, Jenkins, Cella, & Fallowfield, 2019). The social support needed by caregivers include psychological support in addressing the behaviour of cancer patients, which can be quite challenging at times. Helping a caregiver to get a good rest by taking over his/her tasks for a period of time is one of the forms of social support that can be provided (Knapp, Marziliano & Moyer, 2014). To ease the pressure on cancer patient caregivers, they are encouraged to join a support group. Participation in a support group enables members to share and express the forms of stress that they are facing (Goldzweig, Schapira, Baider, Jacobs, Andritsch & Rottenberg, 2019).

Religious elements play an important role in preparing to accept death. When caregivers of cancer patients are firmly rooted in their religious beliefs, the patients are more likely to accept death compared to secular caregivers (Bachner, O'Rourke & Carmel, 2011). Their acceptance of a particular illness or event in their lives is closely related to the social support received by them (Pasek, Dębska & Wojtyna, 2017). Some families of patients use a spiritual and religious approach, which appear to have a positive effect on their efforts to accept the condition of the patients and to manage them throughout the course of their treatment and recovery (Kang, Shin, Choi, Sanjo, Yoon, Kim et al., 2013). This religious and spiritual approach includes being more closely involved in worship activities, visiting houses of worship and also seeking advice from religious members. This has been seen to help improve the well-being of both the caregivers and their patients (Rammohan, Rao & Subbakrishna, 2002).

Methodology

This study used a quantitative approach to obtain the research findings. The study design was determined based on the objective of the study, which required data on the profiles of the respondents and did not involve data in the form of experiences or narratives. The data were collected by means of a survey method, namely through the use of a questionnaire.

This study only focused on the caregivers of cancer patients and did not involve the cancer patients themselves. No interviews were conducted with the cancer patients but the demographic information of the cancer patients was identified to help support the findings. The sample selection method was by way of purposive sampling based on the specified categories, i.e.:

- i. Covering all categories of cancer
- ii. Covering all categories of age and race
- iii. Covering caregivers who are receiving support and those who have never received support from any support group for cancer caregivers.

The respondents involved in this study were primary caregivers of cancer patients from the northern states of Kedah and Perlis. The primary data were obtained through a data collection process. A total of 31 respondents completed the questionnaires which were distributed among the caregivers of cancer patients.

Table 1: *Number of Study Respondents*

Study Respondents	Total Respondents
Social Support Group 1	14
Cancer Patients Support Group 2	12
Caregiver Support Group 3	5

The study instrument used was a questionnaire, which was adapted based on the study by Smoczyk, Zhu and Whatley (1992). In this study, the questionnaire was divided into four (4) sections, namely, emotional support, physical support and spiritual support (social support, organizational characteristics of cancer support groups, constraints as caregivers of cancer patients), and demographic background. The information and data obtained were analysed using a descriptive statistical analysis method, namely, frequencies and percentages, as well as inferential statistical analyses, namely, Pearson's correlation analysis; t-test and ANOVA test.

Findings

Demography

The descriptive analysis in Table 2 shows the distribution of the frequencies and percentages of the demographic profiles of the caregivers. The survey found that 3 respondents (9.7%) were aged between 61 to 70 years, 4

respondents (12.9%) were aged between 51 to 60 years, while 5 respondents (16.1%) were aged between 11 to 20 years and 31 to 40 years, 6 respondents (19.4%) were aged between 41 to 50 years, and the remaining 8 respondents (25.8%) were between the ages of 21 to 30 years. The study showed that 19 respondents (61.3%) were females, and 12 others (38.7%) were males. The findings of this study, shown in Figure 4.3, show that the majority of the respondents i.e., 28 respondents (90.3%), were Malays and only 3 respondents (9.7%) were Chinese.

The results of the study showed that the majority of the respondents, i.e. 18 respondents (58.1%) were educated up to secondary school level, and 9 respondents (29%) were educated up to college or university level, while 2 respondents (6.5%) studied up to other educational levels. There was also one respondent (3.2%) who did not receive any formal education and another respondent (3.2%) who studied up to primary level only.

The results of the study showed that the majority of the caregivers, i.e. 18 respondents (58.1%), had family ties with the patient, while 11 respondents (35.5%) stated that they were the spouses of the patients, and one respondent (3.2%) stated that the relationship with the patient was that of a patient-nurse relationship. There was also one respondent (3.2%) who did not state the relationship with the patient.

This study also showed that 8 respondents (25.8%) stated that their income was between RM901 to RM1500, 6 respondents (19.4%) stated that their income was less than RM900, while 3 respondents (9.7%) stated that their income was more than RM3000. There were 2 respondents (6.5%) who stated that their income was between RM1501 to RM2000. One respondent each stated that their income was between RM2001 to RM2500 and RM2501 to RM3000, respectively. There were also 10 respondents (32.3%) who did not state their income.

Table 2: Demography of Caregivers

Demographic Factor	Category	Frequency	Percentage
Age Categories of Caregivers	11 - 20 years	5	16.1
	21 - 30 years	8	25.8
	31 - 40 years	5	16.1
	41 - 50 years	6	19.4
	51 - 60 years	4	12.9
	61 - 70 years	3	9.7
	Total		31

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Gender	Male	12	38.7
	Female	19	61.3
	Total	31	100
Ethnicity	Malay	28	90.3
	Chinese	3	9.7
	Total	31	100
Education Level	No formal education	1	3.2
	Primary school education	1	3.2
	Secondary school education	18	58.1
	College/university education	9	29
	Others	2	6.5
	Total	31	100
Relationship	Spouse	11	35.5
	Family Member	18	58.1
	Patient and Nurse	1	3.2
	Not stated	1	3.2
	Total	31	100
Occupation Categories	Manager/Administrator	3	9.7
	Support Staff	1	3.2
	Self-employed	5	16.1
	Professional	5	16.1
	Technical Staff	1	3.2
	Others	10	32.3
	Not stated	6	19.4
	Total	31	100
Income	Below RM900.00	6	19.4
	RM901-RM1500	8	25.8
	RM1501-RM2000	2	6.5
	RM2001-RM2500	1	3.2
	RM2501-RM3000	1	3.2
	Above RM3000	3	9.7
	Not stated	10	32.3
	Total	31	100

Descriptive Analysis of Every Variable Based on Forms of Support Levels Required by Caregivers of Patients

A descriptive analysis was also performed to determine the levels of emotional support, physical support and spiritual support required. There were three levels of support, namely, low, moderate and high levels, which were determined according to the total scores that were obtained for each variable that was studied. In addition, a descriptive analysis was also conducted to look at the constraints faced by the respondents throughout their care of the patients as well as the characteristics that were considered to be important in the selection of an appropriate support group.

Emotional Support

The scores for emotional support were between 11 and 44. The scores were divided according to three categories, where the low scores were between 11 and 22, the moderate scores were between 23 and 33, and the high scores were between 34 and 44. In general, the majority of the respondents, i.e. 21 respondents (67.7%), were at a moderate level, while 9 respondents (29%) were at a high level, and only one respondent (3.2%) was at a low level.

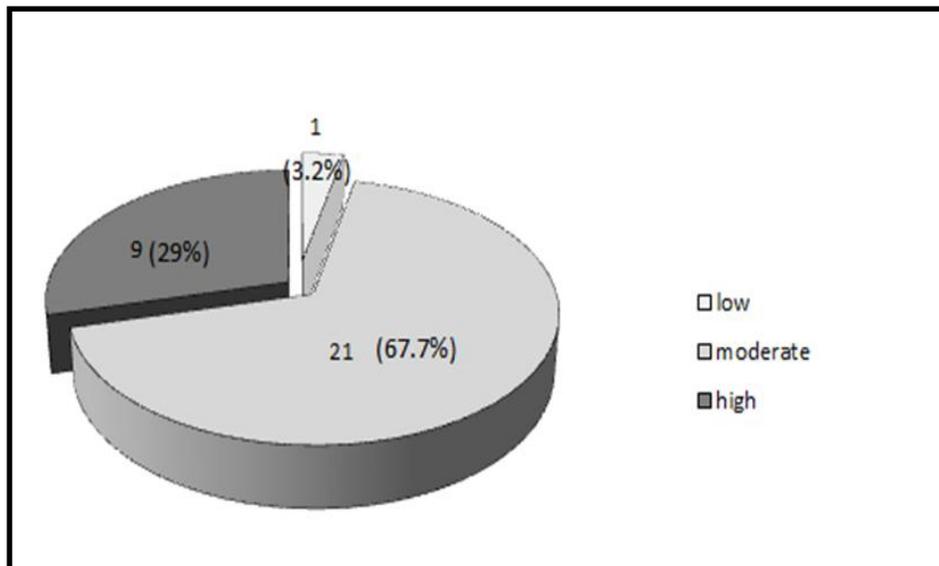


Figure 1: Levels of Emotional Support

Physical Support

The scores for physical support were between 20 and 80. The low scores were between 20 and 40, the moderate scores were between 41 and 60, and the high scores were between 61 and 80. For the levels of physical support, the majority of the respondents, i.e. 23 respondents (74.2%) were at moderate level, while 8 respondents (25.8%) were at a high level.

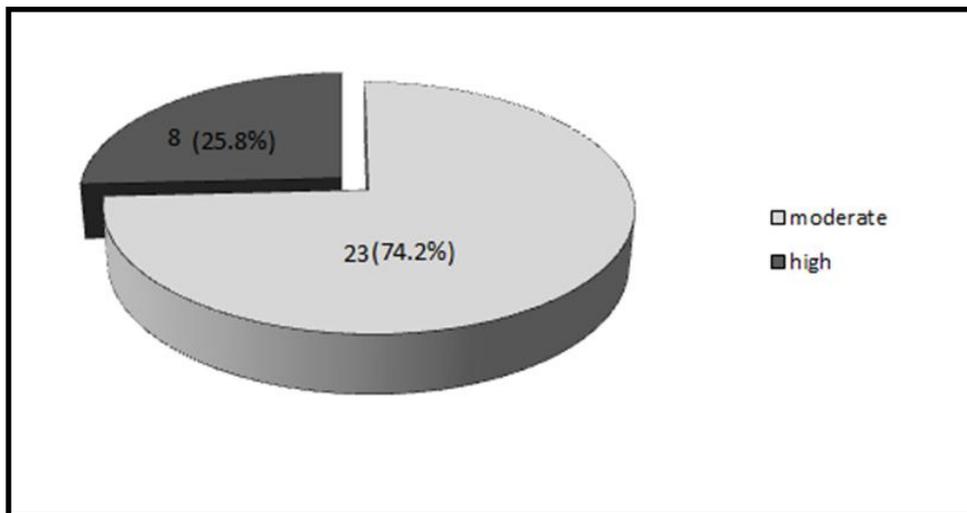


Figure 2: Levels of Physical Support

Spiritual Support

For the spiritual support levels, the scores were between 17 and 68. The low scores were between 17 and 34, the moderate scores were between 35 and 51, and the high scores were between 52 and 68. For the spiritual support levels, the majority of the respondents, i.e. 25 respondents (80.6%) were at a moderate level, while 4 respondents (12.9%) were at a high level, and only 2 respondents (6.5%) were at a low level.

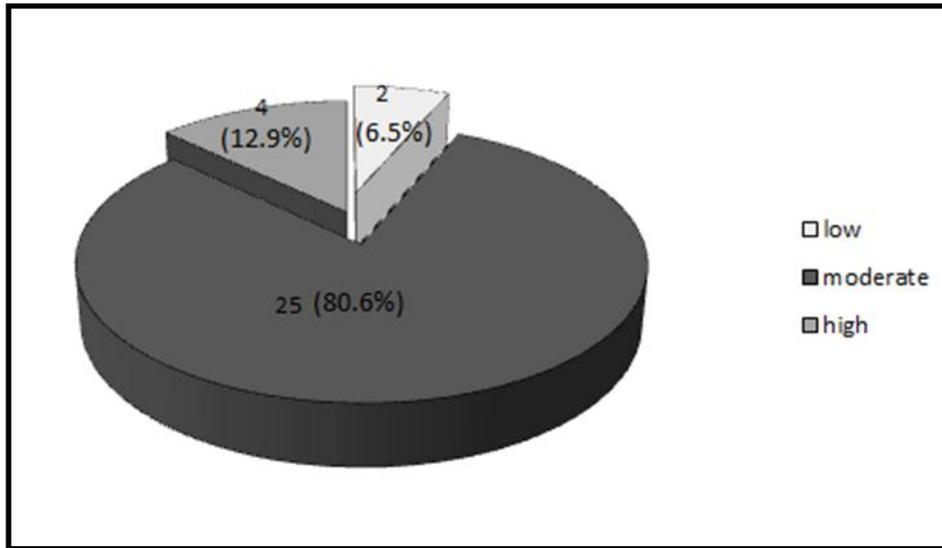


Figure 3: Levels of Spiritual Support

Types of Social Support

Generally, the majority of the respondents, i.e. 21 (67.7%) of the respondents were at the moderate level. There were 9 respondents (29%) at the high level and only one respondent (3.2%) at the low level. When it came to the physical support levels, the majority of the respondents, i.e. 23 respondents (74.2%) were at the medium level, while 8 respondents (25.8%) were at the high level. As for the spiritual support levels, the majority of the respondents, i.e. 25 respondents (80.6%), were at a moderate level, while 4 respondents (12.9%) were at a high level, and only 2 respondents (6.5%) were at a low level.

The perceptions of caregivers with regard to the importance of social support differed according to the selected demographic factors (age, gender, race, education level, duration of care, income).

A t-test was carried out and the results showed that there were no significant differences in the levels of emotional support ($t(31) = 0.439, p > .05$), physical support ($t(31) = .544, p > .05$) and spiritual support ($t(31) = -.053, p > .05$) based on the gender factor.

Table 3: Summary of One-Way ANOVA Test of the Levels of Social Support Based on the Gender Factor

Variable	Gender	N	Mean	Standard deviation	T
Emotional support	Male	12	35.5833	6.12682	0.439*
	Female	19	34.3684	8.24089	
Physical support	Male	12	36.1667	9.94378	.544*

	Female	19	34.2632	9.20653	
Spiritual support	Male	12	27.3333	6.98483	-.053*
	Female	19	27.4737	7.33612	

*p>.05

A t-test was also carried out and the results showed that there were no significant differences in the levels of emotional support ($t(31) = .446, p > .05$), physical support ($t(31) = .383, p > .05$) and spiritual support ($t(31) = .530, p > .05$) based on the race factor.

Table 4: Summary of t-Test for Levels of Social Support Based on the Race Factor

Variable	Race	Mean	Standard deviation	t
Emotional Support	Malay	35.0357	7.42609	.446*
	Chinese	33.0000	8.54400	
Physical Support	Malay	35.2143	9.58532	.383*
	Chinese	33.0000	8.54400	
Spiritual Support	Malay	27.6429	7.34955	.530*
	Chinese	25.3333	4.04145	

*p>.05

An ANOVA test was carried out and the results showed that the levels of emotional support ($F(5,25) = 0.129, p > .05$), physical support ($F(5,25) = 0.753, p > .05$) and spiritual support ($F(5,25) = 1.174, p > .05$) did not differ significantly according to the age factor.

Table 5: Summary of One-Way ANOVA Test of the Levels of Social Support Based on the Age Factor

Variable		Sum of squares	df	Mean squared	F
Emotional Support	Between groups	41.41	5	8.282	0.129*
	Within groups	1604.783	25	64.191	
	Total	1646.194	30		
Physical Support	Between groups	345.617	5	69.123	0.753*
	Within groups	2294.383	25	91.775	
	Total	2640	30		
Spiritual Support	Between groups	286.248	5	57.25	1.174*
	Within groups	1219.3	25	48.772	
	Total	1505.548	30		

*p>.05

The results also showed that the levels of emotional support ($F(4,26) = .918, p > .05$), physical support ($F(4,26) = .655, p > .05$) and spiritual support ($F(4,26) = 1.25, p > .05$) did not differ significantly according to the

education level factor. This showed that there were no differences in the levels of support for the caregivers based on their education level.

Table 6: Summary of One-Way ANOVA Test of the Levels of Social Support Based on the Education Level

		Factor			
Variable		Sum of squares	df	Mean Squared	F
Emotional Support	Between groups	203.694	4	50.923	.918*
	Within groups	1442.500	26	55.481	
	Total	1646.194	30		
Physical Support	Between groups	241.667	4	60.417	.655*
	Within groups	2398.333	26	92.244	
	Total	2640.000	30		
Spiritual Support	Between groups	242.882	4	60.720	1.25*
	Within groups	1262.667	26	48.564	
	Total	1505.548	30		

*p>.05

For the perceptions of caregivers with regard to the importance of emotional support ($F(4,26) = .353, p > .05$), physical support ($F(13,17) = .381, p > .05$), and spiritual support ($F(13,17) = .410, p > .05$) based on the duration of care factor, the one-way ANOVA test results showed that there were no significant differences according to the duration of care factor.

Table 7: Summary of One-Way ANOVA Test of the Level of Social Support Based on the Duration of Care

		Factor			
Variable		Sum of squares	df	Mean Squared	F
Emotional Support	Between groups	349.813	13	26.909	.353*
	Within groups	1296.381	17	76.258	
	Total	1646.194	30		
Physical Support	Between groups	595.143	13	45.780	.381*
	Within groups	2044.857	17	120.286	
	Total	2640.000	30		
Spiritual Support	Between groups	359.048	13	27.619	.410*
	Within groups	1146.500	17	67.441	
	Total	1505.548	30		

*p>.05

After carrying out the one-way ANOVA test to determine the differences in the levels of social support according to the income factor, the results showed that the levels of emotional support ($F(4,26) = 1.525, p > .05$), physical support ($F(6,24) = .690, p > .05$), and spiritual support ($F(6,24) = 2.213, p > .05$) did not differ significantly according to the income factor.

Table 8: Summary of One-Way ANOVA Test of Levels of Social Support Based on the Income Factor

Variable		Sum of squares	df	Mean Squared	F
Emotional Support	Between groups	454.385	6	75.731	1.525*
	Within groups	1191.808	24	49.659	
	Total	1646.194	30		
Physical Support	Between groups	388.400	6	64.733	.690*
	Within groups	2251.600	24	93.817	
	Total	2640.000	30		
Spiritual Support	Between groups	536.215	6	89.369	2.213*
	Within groups	969.333	24	40.389	
	Total	1505.548	30		

* $p > .05$

Discussion, Implications and Suggestions

Discussion

This study was conducted to observe and examine the constraints faced and social support received by the caregivers of cancer patients. A total of 31 respondents were involved in this study, in which the researcher discussed the results of the data analysis that was carried out according to the research questions and the formulated hypotheses, namely, (1) The constraints that are often faced by caregivers in providing care to patients; (2) Studying the forms of social support required by caregivers of cancer patients; and (3) Analysing the differences in the perceptions of caregivers with regard to the importance of social support based on selected demographic factors (age, gender, race, education level, duration of care, and income).

The caregivers of patients comprise spouses or close family members. Due to the close relationship, the age factor is not a problem in terms of the willingness of the caregiver to provide care to the patient. In addition, the pattern of family bonds also plays an important role in shaping the perceptions of the caregivers. This is because the caregivers are more concerned about the love relationship between them and the time they share together is regarded as a happy memory (Mitschke, 2008; Ravies, Karus & Pretter, 1999). When caring for a cancer patient,

the caregiver not only has to help the patient to move about or to prepare the medication, but in addition to that, among the important factors in caring for cancer patients is the ability to communicate well and also to encourage the patient. The results of this study showed that there is no difference in social support based on the factor of gender. Social support is important regardless of gender because every cancer patient caregiver experiences psychological, social, spiritual and physical stress throughout the duration of care as most of them encounter problems with time management and finances, and their emotions are constantly plagued by stress and anxiety.

The results of the analysis showed that only two races were involved in this study, namely, Malays and Chinese. The results also showed that there were no significant differences in social support according to the factor of race. This shows that the burdens and constraints faced by caregivers in managing the patients are capable of affecting their quality of life and well-being (Kim & Given, 2008; Litzelman, Kent, Mollica & Rowland, 2016) and every caregiver needs social support regardless of race. What is important is how each caregiver makes use of the opportunity to obtain the support they require to help ease their duties as caregivers and to meet their social needs (Demirtepe-Saygili & Bozo, 2011; Matthews, Baker & Spillers., 2003; Ravies, Karus & Pretter, 1999). In this study, the caregivers stated that there was no difference in social support according to their education level. This is probably because caregivers always have good communication skills and a close relationship with their patients. This factor also facilitates the caregivers in communicating with the patients while motivating and encouraging them. In addition, sharing in a support group can also help caregivers to gain a new passion and to learn many things about cancer.

The importance of social support does not differ according to the duration of care for the patients because every caregiver needs support from all parties to help them in the care and management of the patient. In the early stages, they need support and encouragement to accept the condition of the patient's illness. Caring for a cancer patient is a huge role and calls for many demands. Caregivers are sometimes unprepared and are constantly on the lookout for the best and most suitable method (Kent, Rowland, Northouse, Litzelman, Wen-Ying, Shelburne, et al., 2006).

Financial resources are one of the major constraints faced by most caregivers of cancer patients. This is because the barriers faced by cancer patients in gaining access to quality services, especially the lack of health insurance

and the inability to pay for treatment-related expenses, also have an impact on both the patients and their families (Burg, Zebrack, Walsh, Maramaldi, Lim & Smolinski, 2010). The results of this study showed that there was no difference in the importance of social support in terms of the income factor. Social support is support in the form of the exchange of information, emotional support, and physical support and also the formation of a network of relationships (Rammohan, Rao and Subbakrishna, 2002). It is felt that the support received can reduce the stress being faced while helping to facilitate the day-to-day management (Cohen, Gottlieb & Underwood, 2000).

Implications

Overall, the researchers discussed the findings of the study and the support from the findings of previous studies. Cancer not only impacts the health but also involves other psychosocial problems including social, economic and psychological relationships. The impact is felt not only by the patient but also the caregivers and family members as a whole that are present in each phase of the cancer. These constraints arise due to the assumptions of the caregivers with regard to the current situation being faced by them. While the caregivers are striving to care for and encourage the patients, they are not aware that their psychosocial health and well-being are also being affected (Okoye, Okoro, Akosile, Onwuakagba, Ihegihu & Ihegihu, 2019).

Social support helps to ease the psychosocial burden being shouldered by caregivers, and also to improve their well-being and quality of life (Okoye et al., 2019; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013). This is because it is through this social support that a person experiences the presence or availability of others who care for, appreciate and love them (Sarason, Levine, Basham dan Sarason, 1983), and establishes a network of relationships (Rammohan, Rao dan Subbakrishna, 2002).

Suggestions

In future, the same study can be carried but with the involvement of more samples and hospitals throughout the country. The focus may perhaps be given to the factor of the culture of the respondents in future studies. This is because it would be interesting to examine the culture factor, and it is felt that the cultural aspect can help to shape the psychological impact on a person. A person's personality is also seen as one of the factors that can be considered to help counteract the constraints that are being experienced. In balancing the social constraints and support, the factors of adaptation and control can also be the focus of future studies.

In addition, future studies can also be conducted using a combination of quantitative and qualitative methods to obtain more comprehensive and detailed results. Interviews may be carried out to further reinforce the findings of the quantitative data to obtain a more detailed picture of the stress, anxiety, depression and well-being of caregivers of cancer patients. Studies can also be carried out on a continuous and long-term basis to observe the effects and changes to the well-being of cancer patient caregivers.

Conclusion

Social support helps to reduce the psychosocial burden that is being borne by caregivers. This is because the caregivers of cancer patients really need the support of the people around them. Social support can also help to improve the well-being and quality of life because through this social support a person will experience the presence and availability of others who care for, appreciate and love them, and establish a network of relationships. The caregivers of cancer patients really need support in the form of the exchange of information, emotional support, and physical support and also, a network of relationships.

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