Cancer Caregivers' Needs for Their Well-Being in the Information Era

Koo Ah-Choo, Peter Charles Woods, Tenku Putri
Norishah Binti Tenku Shariman
Faculty of Creative Multimedia
Multimedia University
Cyberjaya, Malaysia
e-mail: ackoo@mmu.edu.my, p.woods@mmu.edu.my,
tengku.norishah@mmu.edu.my

Ang Kok-Yew
Department of Game Studies, Faculty of Creative Industries,
Sungai Long, Kajang,
Universiti Tunku Abdul Rahman e: angky@utar.edu.my

Teoh Sian-Hoon
Faculty of Education
Universiti Teknologi MARA
Puncak Alam, Selangor
e-mail: teohsian@salam.uitm.edu.my

Chin Weng-Ping
Education Volunteer
Puchong Hartamas, Puchong, Selangor
e-mail: lydiadigitalclassroom@gmail.com

Abstract— **Caregivers face numerous challenges when dealing with chronic diseases such as cancer. Ageing populations and environmental factors account for increasing numbers of people suffering a variety of cancers, and inevitably the increase in caregivers. Caregivers may be the influencers for cancer treatment decisions by patients, hence their needs as caregivers warrant study. This paper focuses on identifying factors of cancer caregivers' needs in the context of an information and communication technology oriented society. A total of 84 caregivers were recruited for the study from two cancer clinics in a hospital, located in Kuala Lumpur. Quantitative research using a survey instrument was conducted. Factor Analysis was used to identify the need factors, that are communication, personal well-being, basic healthcare, information access, coping with change, and learning needs. This study identified the need for improving communication between cancer sufferers and caregivers, from the caregivers' perspective is seen to be crucial. Facilitation on communication needs should be incorporated into any patient-centered healthcare system for establishing a comprehensive healthcare model. Future research is proposed to look more specifically into information, communication and learning needs.**

Keywords- Cancer; caregivers' need; communication; information; factor analysis.

I. INTRODUCTION

Being in the socially connected and information era, caregivers face challenges in selecting and using information for decision making in their caregiving tasks and decisions. Reference [29] identified the importance of health (cancer) literacy for caregivers. They mentioned that "accessing information from the internet may entail additional demands and capacities compared to traditional health literacy due to the factor of competing sources, identifying accurate and trustworthy resources, technological and internet literacy, as well as access to technology and the internet" (p.12). They propose future research could examine various strategies in providing information to caregivers through eHealth modalities. Reference [18] suggested that innovative health education such as mobile learning applications will further expand the context of a smart learning ecosystem for cancer education.

Caregiver is defined as "someone who performs hands-on care and/or provides emotional support to patients, such as a partner, relative or friend" ([6], p. 388). "Formal caregivers typically undergo training and certification, and may inherently have greater health literacy capacities compared to informal caregivers" ([29], p. 12). The term "caregivers" used in this study is to encompass both partners and family caregivers, who are inherently informal caregivers.

Caregivers to elderly recipients have a significant influence on their treatment [17]. Support is needed for caregivers, such as physical, psychological, social, and spiritual [1] [20] and encompass many decades of care for patients with chronic neurological conditions such as multiple sclerosis, Alzheimer's, Huntington's disease, stroke and Parkinson's disease [22]. However, the capacity of informal caregivers to source and utilize information in order for them to perform their tasks is not well understood [30], especially in the current socially connected world. Caregiving tasks are complex. Increasingly, the family and society are aging and the chance of elderly affected by the disease is higher. The roles of family caregivers are multifaceted and understanding their needs are crucial.

The purpose of conducting this study is mainly to identify the cancer caregivers' needs within the context of information seeking and informal learning model. The need factors were adapted based on [6], with additional factors on informal learning in the information era as highlighted in the literature review. The study reported a detailed process of Principal Component Analysis (PCA). The identified need factors may contribute to the model of cancer caregivers' needs in the information era.

In Section II and its sub-sections, the relevant literature is reviewed on the aspects of dealing with cancer, information access on caregiving and cancer caregivers' needs. The rest of the sections report the methods, analysis and findings, discussions, conclusion and future works of the research.

II. LITERATURE REVIEW

A. *Dealing with cancer*

Annual cancer cases globally are expected to rise from 14 million in 2012 to 22 million within the next 2 decades [26]. Cancer rates increase according to age [16]. A total of 18,219 new cancer cases were diagnosed in 2007 and registered with the Malaysia National Cancer Registry, with 8,123 (44.6%) males and 10,096 (55.4%) females [16].

Giving care to cancer patients is a challenging task for family caregivers [2] [20]. Informal caregivers are untrained [22]. This affects the quality of care in a patient-centred care model, especially when the care is carried out at home without the guidance or support from healthcare professionals. There is a need to increase the awareness of cancer care for caregivers.

According to the President and Medical Director of National Cancer Society Malaysia (NCSM), Dr Saunthari Somasundaram, there is a need to provide awareness about the misconceptions and myths around cancer in Malaysia's culture, and requires a 'whole-of-society' approach to tackle this issue [3] [10]. Prompt actions need to be taken on the misconception to decrease the risk of cancer, and detect cancer earlier for faster access to treatments. Reference [8] urged that the cancer care system in Malaysia requires an urgent reform as their study found that "…Out of the 2,312 deaths due to breast cancer, 2,048 (88%) were avoidable. Of these avoidable deaths, 1,167 (57%) were attributable to late stage presentation while 881 (43%) were due to lack of access to optimal treatment" (p.32). This statistic shows an under-performing outcome of the cancer care system in Malaysia. Reference [8] further identified a Malaysian cancer divide between the rich and poor, mirroring the global cancer divide between rich and poor countries. They said, "…the huge number of avoidable deaths highlights the high cancer mortality rate among the deprived and the vast disparity in access to cancer care between the rich and poor within Malaysia." (p.32)

Dealing with the cancer demands both the management of the disease and its consequences emphasise that "cancer is a societal issue and is not confined to health" [28], which undoubtedly needs more attention in research. The social groups for cancer support could play a more proactive and important role to promote early treatment or disseminate accurate information about cancer. There is also a need for palliative care to reduce caregivers' burden [1] [4]. Compared to caregivers of other types of illnesses, cancer caregivers spend more hours providing care and the intensity of their caregiving is increasing due to the nature of active treatments. They are definitely in need of assistance and information to make the best decision regarding cancer treatments [11]. The length of time spent on caregiving determines the stress levels among the caregivers. Access to caregiving support in the society or community is often limited in Asian countries. According to [28], support was mainly acquired through non-governmental organizations (NGOs). Access to integrated care that extends from hospitals to the community is lacking, especially for healthcare needs, and trustable informational needs [28]. Access to information is mostly informal, influenced by many viewpoints, ranging from information provided by medical professionals, to information retrieved from the internet, friends, family, and social media sites that are often conditioned by the belief system grounded within the various cultural groups. These multiple views clearly pose a challenge for patients to make wise treatment decisions. It is the responsibility of the government, civil society and communities to support the process and education of patients and caregivers in dealing with cancer. Healthcare expenses have risen in recent years, hence cancer care is a financial burden for most households and the country [13]. Treatment costs in the first year after diagnosis can exceed 30% of household income in ASEAN countries [13] [28].

B. *Information access on caregiving: A mixed blessing*

We acknowledge the idea of a Seamless Learning Model in the context of caregivers' informal learning and information seeking pursuits, implemented seamlessly via the internet and social media, which impacts their public and private learning spaces. Many activities of learning and information seeking, especially for caregivers are inherently informal, self-directed, independent, and critical as they are frequently influenced by online technologies and social media. There are many internet-based information platforms for supporting and developing skills in caregiving and social care, for example [33] [34] [35]. It is also recognized as an authentic and just-in-time learning (or training), especially for caregivers or informal caregivers who need some help and guidance during challenging times.

Many countries have developed their national health websites and awareness programs to spread knowledge about healthcare and promote a healthy lifestyle by using the internet and social media platforms (e.g., Myhealth Portal and Infosihat for Malaysia; Singapore Health Promotion website). However, according to [2] (p. 627), the importance of these online media and technologies has not been clearly revealed in previous studies, especially on the information-seeking behavior of family caregivers. More research should be conducted to add literature on the information seeking behaviours among caregivers.

Through seamless technologies, [21] propose the use of tools to design diverse learning experiences such as creating extended learning communities, linking people in real and virtual worlds (connectedness), providing expert knowledge based on demand, and to supporting learners in many ways. Reference [14] proposed a Seamless Learning Framework (Figure 1) to explain the learning environments or dimensions experienced by most of the learners. The learning space is no longer defined by a "physical / formal class" but by "learning unconstrained by scheduled class hours or specific locations" (p.156), thus promoting seamlessness, with informal learning and information access at learners' fingertips. The seamless environment is labeled as "community" which comprises different categories of people such as teachers, experts and learners. The community has access to any relevant sources of knowledge through cognitive tools, within the dimension of time (anytime), space (anywhere), and artefacts (any learning artifacts / contents).

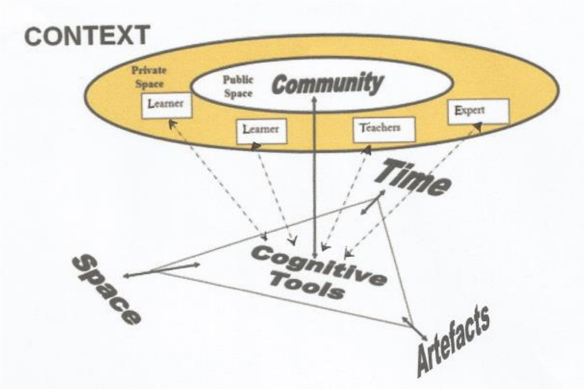

Figure 1. A Seamless Learning Framework [14].

This concept can be applied to fulfil the informal learning needs of cancer caregivers since caregivers interact with all kinds of information and materials seamlessly. They interact with internet support groups or cancer survivors through social media; and also conduct discovery learning about the disease from the cancer journeys shared by others. There are also professional cancer learning and sharing materials which can be accessed with ease.

The internet is a 'mixed blessing' for the healthcare sector. Reference [25] suggested that public health information campaigns could be conducted using social media. This new means of communication, especially for prevention purposes, will complement other methods of communication. However, the challenge will be to adhere to the legal framework that preserves the quality of the healthcare information provided on the internet.

Consumption of online healthcare information and services is increasing [15] and has empowered caregivers (and patients) to enhance their health literacy for improved decision making [9].

Reference [18] conducted a quasi-experimental effectiveness study of a new mobile learning tool for cancer education and the results showed that the application has significantly increased cancer prevention knowledge among the users. However, the main drawback of online healthcare information is its credibility. Diagnostic information online is sometimes used to confront doctors [12] [15]. Reference [15] suggested that users, such as caregivers must critically analyze and select information posted on YouTube in order to make effective healthcare decisions.

A. *Cancer caregivers' need*

Reference [19] - Seattle Cancer Care Alliance (2013) listed the challenges of caregiving: caring for themselves (self-care), supporting and caring patients emotionally and physically, maintaining the home environment for patients, gathering information, helping with decision-making on cancer care or treatment, arranging patients' hospital visits and patient's financial support. These tasks are complex especially for the new caregivers. Roles of family caregivers are multifaceted, and adequate support is required for them (Glajchen 2004 in [2]). According to Wingate and Lackey cited in [2], family caregivers need knowledge, information, or understanding that can be gained through education, experience, study, or through explanations by qualified cancer specialists. Reference [2] reported a qualitative study that discloses the information needs of cancer family caregivers are varied along the cancer journey, and they used diverse information sources, including healthcare professionals, hospital booklets, interpersonal networks, besides the internet, mass media, and books - to satisfy their needs. Her study found that demographic variables of caregivers (such as gender, age, level of education, socioeconomic status and culture) affected their information-seeking behaviors.

Reference [6] measured the psychometric properties to capture the multidimensional supportive care needs of cancer caregivers. The instrument used was given to 547 cancer caregivers. Psychometric analyses found four dimensions of need: healthcare service, psychological and emotional, work and social, and information. Individuals with anxiety and depression were more likely to report at least one unmet moderate or high need in comparison to non-anxious participants. Younger participants experienced at least one unmet moderate or high need in the area of "psychological and emotional", and "work and social", as compared to the older participants. Reference [6] suggested the findings can be used to prioritize healthcare resources and tailor supportive cancer care service accordingly.

In summary, the study intends to explore the properties or dimensions of needs faced by caregivers, especially the four dimensions namely healthcare service, psychological & emotional, work & social, and the last dimension is the information need. Additional dimension of learning need is also an interest of the current study.

III. METHODS

A survey was conducted in a hospital with two cancer specialist clinics run by NCSM, an NGO for cancer awareness and cancer care. Permission was granted from NCSM in order to conduct this study at the waiting lounge of the two cancer clinics. The population of the study involved all cancer clinics run by NCSM across the country. However, only two cancer clinics were purposively selected to participate in this study due to their strategic location in the center of Kuala Lumpur city. A total of 84 participants were involved in this study. Majority of them were Malaysian Chinese. This is because the hospital is traditionally or historically relevant and popular among Malaysian Chinese community. In addition, the Chinese in Malaysia have the higher lifetime risk for cancer compared to Indians and Malays. Chinese is the second largest ethnic group in Malaysia who form approximately 24 percent of the Malaysian population [16].

Previous reports of the National Cancer Registry (NCR) [16] have revealed that cancer seems to be predominant among Chinese as compared to Malay and Indian. "The Age-Standard-Rate (ASR - a measure for cancer incident) for Chinese male was 111.9 per 100,000 and for Chinese females was 115.0 per 100,000 while for Indian male was 68.2 per 100,000 populations and for females was 99.9 per 100,000 populations." [16] (p. 23). According to the same report, "the

ASR among Malay male and female were 66.9 per 100,000 and 79.0 per 100,000 populations respectively." (p. 23)

A. Instrument

The instrument of the survey was adapted from [6] to study needs in the context of informal learning environments. Items related to this context were added to the instrument. The instrument was then reviewed by three experts in the area of wellness and preventive medicine (Expert 1), management of a cancer wellness center (Expert 2), and healthcare informatics (Expert 3) respectively. Items were reviewed; some were dropped and merged because of overlapping meaning; some were rephrased for the suitability of local caregivers in Malay and English.

The items were analysed using factor analysis. Factors on the needs of cancer caregivers were then identified in the analysis. There are two key sections of the questionnaire:

Section A – Profiles, caregiving experiences and online activities behavior, Section B – Needs measured by Likert-type items, adapted mostly from [6], that is ranging from "1 denotes no need (either satisfy or non-applicable), 2 denotes low need, 3 denotes moderate need, and 4 denotes high need".

B. Procedures

The caregivers in the waiting lounge were invited to participate in the survey. The researcher assistant took turns to be in the waiting area for two or three days in a week for two months. The data collection process stopped when there were very few new caregivers in the waiting area.

Caregivers who agreed to participate in this study were asked to sign a participation consent form. They were briefed that at any time, they could freely withdraw from the study. Some caregivers were assisted by the researchers to clarify the meaning of items. Overall, the total number of usable responses was 84 out of 91; seven responses were not included due to incompleteness.

IV. ANALYSIS AND FINDINGS

There are two main stages of factor analysis conducted for extracting and determining factors in this study. Firstly, factor extraction was performed focusing on making initial decisions about the number of factors that primarily satisfies a set of measured variables based on the Principal Component Analysis (PCA). Secondly, factor rotation was conducted to ensure the underlying factors were more interpretable.

A. Description of the demographic information

More than half were females, the majority of them were Chinese (83%) with their religion Buddhism or Taoism, middle income or lower (77%), holding diploma and above (59%), aged more than 30 years old (73%). More than half of them (62%) have been caregiving for 6 months and above, mostly the care recipients were affected with female related cancer (54%). The caregivers were quite active online to look for health information and connection with others via online. About 60% of them were in this category.

B. The steps of factor analysis

Factor analysis was employed to establish factors of needs, through extracting factors and factor rotation procedures as recommended [24]. Principal Component Analysis (PCA) is chosen because it is a common method for exploring loadings of survey items into the components and it is frequently used in research of education and psychology [23] [24]. The PCA allows transformation of a set of inter-correlated variables into specific components or factors to extract distinct factors from the variables in the analysis which involves reduction of dimensionality among the variables. In the process of extracting factors, suitability of data was tested, and hence actual component extraction was retrieved for getting a smaller number of items to best represent relationships among those items.

1) Stage one: Extracting factor

In PCA, the suitability and adequacy of data in terms of variability of data were tested based on Kaiser-Mayer-Olkin (KMO) measure of sampling adequacy. In this study the value of KMO is 0.842 which is greater than 0.7 which indicates a very good condition to proceed with the factor analysis. In normal practice, the value of KMO should be larger than 0.5 for achieving a condition of satisfactory.

On the other hand, the Bartlett Test of Sphericity takes consideration of testing of correlations among the variables. This value is referred to ensure that there are sufficient correlations among the variables. The sufficiency of correlations is indicated in the associated probability in the chi-square. If the p value of the associated chi-square statistic is less than 0.5, it shows the items are sufficiently correlated for further analysis in PCA. In this study, the results of Bartlett Test of Sphericity show that value of chi-square is 2470 with df=703 and p-value < 0.05, indicating that the variables were sufficiently correlated to form the specific components and factors.

TABLE 1. KMO AND BARTLETT'S TEST.

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.842
Bartlett's Test of Sphericity	Approx. Chi-Square	2470.094
	Df	703
	Sig.	.000

The number of extracted factors or components is determined from variances explained among the variables. The factor extraction also depends on eigenvalues. An eigenvalue is the variance or the variables accounted for by a factor. The six components which have eigenvalues more than one (namely between 1.187 $\approx$1.2 to 16.714$\approx$16.72) were selected into the factors. These values provide a guide to ensure that the variances of components are all contributed from more than a single observed variable (item).

In this study (Table 2, refer to the last page of this paper), the examination of the total variance explained by the components extracted were displayed in Table 2: An analysis of the total variance explained by components (refer to the last page of this article). Component 1 shows a very high eigenvalue and a high percentage (14.57%) of variance explained. Component 2 until component 6 has the total variance explained value of greater than 3% (both for Initial Eigenvalue column and other columns) were chosen. Other components have lower value of initial eigenvalue, which are lower than 1.187 (or its initial percentage of variance explained, which are lower than 3%, i.e. the bold number) are not planned to be selected for the next step of analysis. Thus, the six factors are explained with the total variance 64.1%.

An examination of the scree plot of the Eigenvalue versus Component has shown a clear "knee point / elbow", that is at the point of component number of 6 (refer to Figure 2). Other components have lower eigenvalue, which will not be considered for the next step.

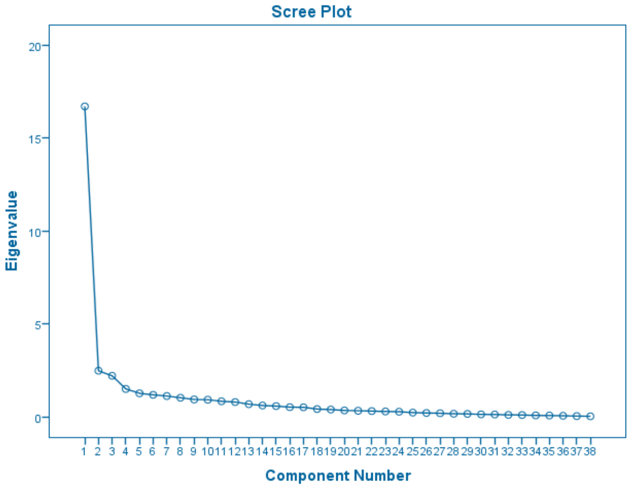

Figure 2. Scree plot showing the elbow at the point of the sixth component at the value of Eigenvalue >= 1.

2) *Stage two: Factor rotation*

The final step of PCA is to examine the factor loadings of each item in relation to the first six components. The factor loading presents the results of component rotations and interpretation of components.

The factor rotation method used in the analysis is Varimax rotation, a method used frequently in social science and psychological study. A check on oblique based rotation has also produced the similar set of items according to these components. In determining the factors from the factor loading, the loading of absolutes 0.4 is used as a cut-off value [7]. For practical significance, loadings of absolutes0.4 and above, but less than 0.5 are considered just enough to be significant. Loadings above 0.5 indicate highly significant. On the other hand, if the factor loading difference between two factors across a particular item is less than 0.2, the item should be dropped.

Table 3 is a matrix table showing the rotated components and their related items shows the loading value of each item which are greater than 0.4 in relation to the six identified components in the factor extraction, and other components (i.e. Components 7 and 8). The bold loading values are the selected items according to components; items which loading values are *italicized* due to the difference of loading values less than 0.2 were discarded (i.e. Item 18, 35, 26, 33 and 32). Components 7 and 8 were also not considered for interpretation.

TABLE 3. A MATRIX TABLE SHOWING THE ROTATED COMPONENTS AND THEIR RELATED ITEMS WITH FACTOR LOADINGS.

Item #	1	2	3	4	5	6	7	8	Difference of two factor loadings with nearest values	Decision on item#
14	0.819									
13	0.809									
19	0.658									
29	0.641									
20	0.622									
18	*0.575*				*0.433*				0.142 (<0.2)	Item 18 is dropped from analysis
15	0.469									
30		0.769								
27		0.766								
36		0.701								
28		**0.679**			**0.456**				**0.223 (>0.2)**	**Item 28 is maintained**
25		**0.638**			**0.424**				**0.214 (>0.2)**	**Item 25 is maintained**
10		0.611								
35		*0.593*	*0.467*						0.126 (<0.2)	Item 35 is dropped from analysis
26		*0.546*			*0.448*				0.098 (<0.2)	Item 26 is dropped from analysis
9			0.656							
6			0.605							
7			0.54							
33	*0.411*		*0.518*			*0.426*			0.015 (<0.2)	Item 33 is dropped from analysis
32			*0.515*		*0.486*		*0.432*		0.054 (<0.2)	Item 32 is dropped from analysis
8			0.476							
11			0.462							
5			0.45							
12			0.44							
3				0.783						
1				0.781						
2				0.706						
4			**0.425**	**0.64**					**0.215 (>0.2)**	**Item 4 is maintained**
24					0.787					
23					0.732					
17					0.506					
37						0.814				
38						0.809				

34						0.594				
21							0.757			
31			*0.429*				*0.444*		0.015 (<0.2)	Item 31 is dropped from analysis
22								0.624		
16					*0.418*			*0.5*	0.082 (<0.2)	Item 16 is dropped from analysis

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 10 iterations.

Note: The minimum loading score accepted is 0.4, loadings below 0.4 are not shown; *items with loading difference <0.2 are discarded from further analysis / interpretation*. Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. A. Rotation converged in 10 iterations.

The bold items were retained and used for interpreting the need factor. In total, there were 29 items to explain six (6) components of need factors. Table 3 shows a matrix of the rotated components and their related items. A total of 9 items were discarded, and not included for further interpretation of the construct or need factors.

The internal reliability analyses with the Cronbach's Alpha values for the items emerged for six components / factors are stated in column 3 of Table 4: Factors with items loaded to the six-factor of needs (Refer to the last page of this paper). All factors have the alpha values greater than 0.7 ($\alpha > 0.7$), indicating an acceptable internal reliability measure for the factors.

Collectively, none of the factors scored 'high need' and there is no factor indicating "no need". The need for communication is at the level of 'moderate'. Other need factors such as personal well-being, basic healthcare, access to information, coping with change are between 'low' to 'moderate need'. The need for learning through online information and connection is 'low'.

V. DISCUSSION

Six-factor of needs were identified in this study; they are:

- Factor 1 (F1): Regular communication for better understanding and balance of needs between caregivers and person with cancer;
- Factor 2 (F2): Personal well-being especially on the control of emotion, communication and spiritual beliefs mainly on the quest of meaning of life and the faith in the healing process;
- Factor 3 (F3): Basic healthcare, counselling and service;
- Factor 4 (F4): Access to information related to cancer or patient care information and Services;
- Factor 5 (F5): Coping with change especially the change of life routine and perspective on life;
- Factor 6 (F6): Learning through online information and connection with others on cancer care.

These factors are aligned with the study conducted by [6] which proposed four domains of need, namely Healthcare Service (F3 of the current study), Psychological and Emotional (F2 and F5 of the current study), and Information (F4 of the current study). The last factor by [6] is Work and Social Needs. This factor was not emerged in the current study.

A. The emergence of communication as a more important need factor

The current study has revealed that Communication (F1) is a more important need factor. Communication shows the highest percentage of variance explained. Its mean value also shows the highest need compared to other factors.

Reference [5] argued that, "…effective communication for cancer patients and/or caregivers can meet information needs, reduce caregiver burden, improve physical and mental health, and promote intimacy." (p. 1) According to their critical review findings, the communication needs identified are multifaceted nature of cancer patients and/or caregivers in terms of communication target, content, style, timing, and preferences. For example, communication targets included health professionals, peers, caregivers, and patients. Communication content included illness-related, emotional support, daily life, sexuality, death, and a way to communicate with health professionals [5].

Other major contributing factors of need are Psychological and Emotional (F2) and Healthcare Service (F3). By taking emotional support as an example, evidence shows that both negative and positive emotions are important in communication [32]. A study found that cancer patients who expressed negative emotions and received an empathetic response from their oncologist perceived communication as being more favorable [31].

Reference [30] found the caregivers' needs which are: 1) accessing and understanding the information, 2) relationship with healthcare providers, 3) relationship with the care recipient, 4) managing challenges of caregiving and support systems. Other areas of need mentioned by [30] are basic healthcare, communication with care recipients, and support systems; these needs are also aligned with the findings of the current study.

According to [30], caregivers' health literacy is multidimensional. The current study has also found the need for multidimensional support for caregivers and their personal well-being. Support is not just on communication or personal well-being, but also involves other needs such as health and physical care, finance, dietary, learning and access to information and supportive people. They need guidance in communication for their preferred way or form of counselling methods. They need a credible source of information through consultation with their healthcare professionals. Caregivers need to communicate with the cancer patient and their family members.

One factor found is the need for coping with change especially the changes to the life routine and perspectives on life. The study in [27] also identified the need for coping with change. In their study, they observed that detection of "cancer creates the context for the caregiver's relationships (with patient, and the healthcare system), and the cognitive, behavioral, affective, and spiritual responses" (p.775); the caregiver's prior experiences and social support network influence the caregivers' perception towards the diagnosis, relationships, and personal responses. Mainly there is a need to cope with change in relationships among key parties who are involved in a patient-centered healthcare system, such as the healthcare providers, doctors, friends and relatives and the communities.

B. Learning need through online information and connection

The current study identified “learning through online information and social connection” as an emerging factor of need. Some input from open feedback indicated that online technologies can be used for seeking “reliable” information about cancer care, healthy lifestyle and diet. However, it is at the lower need level compared to other needs which are more critical during the caregiving period. This could be due to the support by doctors and healthcare teams to provide reliable information that are able to meet their needs.

Overall implication is that the present study has identified six-factor needs with communication need being perceived higher among all factors. The authors discovered that communication need is multifaceted, with communication target, content, style and timing should come at the right and in guided ways. Effective communication with the person with cancer, the other family members and healthcare professionals should be considered the aspect influencing caregivers’ well-being. Usually, the content and style of communication are often neglected. This study found the various aspects of communication to be complex but interesting for future research.

C. Limitations

The study has sampling limitations, the caregivers are mostly from one ethnicity and the number of respondents is less than 85. Most of the samples are from the middle income group, which biases towards the needs for financial and healthcare. The convenience sample for this study comes from one hospital. The type of cancer patients and their caregivers were selected purposively from cancer clinics in a hospital, they were affected by different kinds of cancer. Hence, it is difficult to gather data of different samples based on different cancer types due to sampling limitations. All these limitations are acknowledged. Future research is proposed to incorporate more participating hospitals and caregivers.

VI. CONCLUSION AND FUTURE WORK

The study provides a systematic approach of identifying needs of cancer caregivers. The factors derived from this study have not only highlighted the common domain of needs such as Basic Healthcare, Access to Information, Psychological and Emotional (personal well-being, coping with change), but also encountered other need factors, namely communication and learning need which are corroborated with some scholar works such as [5], Yuen et al.’s works [29] [30] and the works by [14] respectively. These factors should also be considered for any policy decisions or training modules for caregivers, in line with the importance of a seamless learning model in health education. The need factors found are proposed to be incorporated into the patient-centered healthcare system for creating a more comprehensive healthcare model in cancer care involving the support towards the needs of caregivers. This study can be a source of information or as an added literature for cancer caregivers’ needs.

Future directions of this research will consider to study further on one or two aspects of well-being dimensions, for example on trustable information need in decision making. Future research will also consider the different duties of caregivers and the level of quality of treatment received by patients. These variables may influence the requirement of needs by caregivers and subsequently affect the quality of life for the family.

ACKNOWLEDGEMENT

The authors would like to express gratitude for the support given to the research team by Malaysia Ministry of Higher Education (MOHE)’s Fundamental Research Grant Scheme (FRGS) support to this research work. Our appreciation also goes to National Cancer Society Malaysia (NCSM) for their support to the data collection process. Thanks to all the research respondents who were going through the experiences of giving care to their loved ones. Finally, we also would like to thank the anonymous reviewers (all of them) for providing constructive feedback to this paper.

REFERENCES

[1] M. K. Barton, “Earlier adjuvant therapy is beneficial in patients with breast and colon cancer,” CA: A Cancer Journal for Clinicians 0(0): n/a-n/a. 2015. [Online]. Available from: http://doi.wiley.com/10.3322/caac.21296 (assessed 20 July 2016)

[2] S. Chen, “Information needs and information sources of family caregivers of cancer patients,” Aslib Journal of Information Management, vol. 66(6), pp. 623–639, 2014.

[3] T. Carmillia and M. Sivasothy, “Quality end-of-life cancer care. Health and Living Live Forum” BFM: The Business Station. [Retrieved: August, 2020] Available from: https://www.bfm.my/health-and-living-live-2018-part-2-quality-end-of-life-cancer-care.html

[4] J. N. Dionne-Odom, A. Azuero, and K. D. Lyons, “Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomized controlled trial,” *Journal of Clinical Oncology, vol.* 33(13), pp. 1446–1452, 2015.

[5] J. Li et al. 2020. “Communication Needs of Cancer Patients and/or Caregivers: A Critical Literature Review,” Journal of Oncology, vol. 2020, 12. https://doi.org/10.1155/2020/7432849

[6] A. Girgis, S. Lambert, and C. Lecathelinais, “The supportive care needs survey for partners and caregivers of cancer survivors: Development and psychometric evaluation,” Psycho-Oncology, vol. 20(4), pp. 387–393, 2011.

[7] J. F. Hair, R.E. Anderson, R. L. Tatham, and W. C. Black, “*Multivariate Data Analysis*,” New Jersey: Prentice-Hall, 1998.

[8] G. F. Ho, N. A. Taib, R. K. Pritam Singh, C. H. Yip, M. M. Abdullah et al., “What if all patients with breast cancer in Malaysia have access to the best available care: How many deaths are avoidable?” Global Journal of Health Science, vol. *9*(8), 32, 2017. Available at http://doi.org/10.5539/gjhs.v9n8p32 (accessed 10 June 2016)

[9] M. Househ, E. Borycki, and A. Kushniruk, “Empowering patients through social media: The benefits and challenges,” *Health Informatics Journal*, vol. 20(1), pp. 50–58, 2014.

[10] M. Kasmiah, “Creating greater awareness,” *New Straits Times Life & Times*, 25 May, p. 7, 2013.

[11] E. E. Kent, “Cancer caregivers face more stress & depression,” [Retrieved: June, 2018]. Available from: http://www.cancer.net/blog/2016-

09/importance-palliative-care-patients-and-caregivers-news-2016-palliative-care-oncology-symposium

[12] K. Krishna, “A heavy responsibility for Dr H. Krishna Kumar,” Fit For Life “People” *Sunday Star*, 3 August, pp.10, 2014

[13] H. W. Lee, T. Ramayah, and N. Zakaria, “External factors in hospital information system (HIS) adoption model: A case on Malaysia,” *Journal of Medical Systems, vol.* 36(4), pp. 2129–2140, 2012.

[14] C. K. Looi, P. Seow, and B. Zhang, “Leveraging mobile technology for sustainable seamless learning: A research agenda,” *British Journal of Educational Technology, vol.* 41(2), pp. 154–169, 2010.

[15] K. C. Madathil, A. J. Rivera-Rodriguez, and J. S. Greenstein, “Healthcare information on YouTube: A systematic review,” *Health informatics journal, vol.* 21(3), pp.173–94, 2015.

[16] Malaysia Ministry of Health (MOH), “National Cancer Registry Report 2007”. Putrajaya Malaysia, 2007.

[17] R. M. Razali, P. C. Bee, and G. G. Gan, “Survey of willingness to accept chemotherapy among elderly Malaysian patients,” *Asian Pacific Journal of Cancer Prevention, vol.* 14(3), pp. 2029–2032, 2013.

[18] N. Ribeiro, L. Moreira, A. M. P. Almeida and F. Santos-Silva , “Mobile Seamless Learning Tool for Cancer Education,” In: Mealha Ó., Divitini M., Rehm M. (eds) Citizen, Territory and Technologies: Smart Learning Contexts and Practices. SLERD 2017. Smart Innovation, Systems and Technologies, vol. 80. Cham: Springer, 2018.

[19] Seattle Cancer Care Alliance, “Patient & Family Education: Companion Guide for Caregivers and Family Members,” 2013. Available from: http://www.seattlecca.org/client/patient-education/SCCA-Companion-Guide-for-Caregivers.pdf (accessed 1 August 2016)

[20] P. Sercekus, D. B. Besen, and N. P. Gunusen,, “Experiences of family caregivers of cancer patients receiving chemotherapy,” *Asian Pacific journal of cancer prevention : APJCP,* vol. 15(12), pp. 5063–5069, 2014.

[21] M. Sharples and J. Roschelle “Guest Editorial Special section on Mobile and Ubiquitous Technologies for Learning,” *IEEE Transactions on Learning Technologies,* vol. 3(1), pp.4-6, 2010.

[22] A. B. Sullivan and D. Miller, “Who is Taking Care of the Caregiver?”, *Journal of Patient Experience*, vol. 2(1), pp. 7–12, 2015. Available at http://doi.org/10.1177/237437431500200103

[23] S. H. Teoh, A. C. Koo, and S. Parmjit, “Extracting factors for students’ motivation in studying mathematics,” *International Journal of Mathematical Education in Science and Technology, vol.* 41(6), 2010. 711-724. *International Journal of Mathematical Education in Science and Technology* 41(6): pp. 711–724, 2010.

[24] The Rocky Mountain University of Health Professions (RMUoHP) Biostatistics Resource,“How to use SPSS: Factor Analysis - Principal Component Analysis,” [Video file]. Available from: https://www.youtube.com/watch?v=UWP9OEoaNnE

[25] I. Veuillotte, G. Morel, and S. Pitois, “General practice and the Internet revolution. Use of an Internet social network to communicate information on prevention in France,” *Health informatics journal,* vol. 21(1), pp. 3–9, 2015.

[26] WHO Media Center, *Cancer,* 2015. Available at: http://www.who.int/mediacenter/factsheets/fs297/en/ (accessed 5 August 2016).

[27] A. Williams and M. Bakitas, “Cancer Family Caregivers: A New Direction for Interventions,” *Journal of Palliative Medicine*, vol. 15(7), pp. 775–783, 2012.

[28] M. Woodward, “A consensus plan for action to improve access to cancer care in the Association of Southeast Asian Nations (ASEAN) region,” *Asian Pacific Journal of Cancer Prevention, vol.* 15(19), pp. 8521–8526, 2014.

[29] E. Y. N. Yuen, T. Knight, L.A. Ricciardelli, and S. Burney, “Health literacy of caregivers of adult care recipients: A systematic scoping review,” *Health and Social Care in the Community*, pp. 1–16, 2016. Available from: http://doi.org/10.1111/hsc.12368 (accessed 10 August 2016)

[30] E. Y. N. Yuen, S. Dodson, and R.W. Batterham, Development of a conceptual model of cancer caregiver health literacy. European Journal of Cancer Care (December 2014), 2015. Available from: http://doi.wiley.com/10.1111/ecc.12284 (accessed 8 August 2016)

[31] C. Malhotra, R. Kanesvaran, L. Krishna, et al., “Oncologists’ responses to patient and caregiver negative emotions and patient perception of quality of communication: results from a multi-ethnic Asian setting,” *Supportive Care in Cancer,* vol. 26(3), pp. 957–965, 2018

[32] A. L. Terrill, L. Ellington, K. K. John, et al., “Positive emotion communication: fostering well-being at end of life,” *Patient Education and Counseling*, vol. 101(4), pp. 631–638, 2018.

[33] Cancer.Net Website [Retrieved: August, 2020] https://www.cancer.net/ cancer.net

[34] Skill For Care Website [Retrieved: August, 2020] https://www.skillsforcare.org.uk/About/About-us.aspx

[35] Dignity In Care Website. [Retrieved: August, 2020] https://www.dignityincare.org.uk/About/

TABLE 2. AN ANALYSIS OF THE TOTAL VARIANCE EXPLAINED BY COMPONENTS.

Total Variance Explained									
Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	16.714	43.984	43.984	16.714	43.984	43.984	5.537	14.571	14.571
2	2.483	6.536	50.520	2.483	6.536	50.520	5.267	13.862	28.433
3	2.211	5.817	56.337	2.211	5.817	56.337	4.016	10.568	39.001
4	1.504	3.957	60.294	1.504	3.957	60.294	3.408	8.969	47.970
5	1.270	3.342	63.636	1.270	3.342	63.636	3.382	8.900	56.870
6	1.187	3.124	66.760	1.187	3.124	66.760	2.738	7.206	64.076
7	1.121	2.949	69.709	1.121	2.949	69.709	1.664	4.379	68.455
8	1.031	2.712	72.421	1.031	2.712	72.421	1.507	3.967	72.421
9	.938	2.468	74.889						
10 **	.924	2.431	77.320**						
Extraction Method: Principal Component Analysis.									

** This table only shows up to 10 components, and did not show all 38 components or up to 100% cumulative value of total variance explained due the space limitation. The bold numbers indicate an acceptable value for the percentage of variance explained for this study. The items cluster into these six groups defined by the highest loading on each item.

TABLE 4. FACTORS WITH ITEMS LOADED TO THE SIX-FACTOR OF NEEDS.

Factor # and its interpretations (Factor Name)	Item # and Item Statement	Mean (Stad. Deviation) Internal reliability Cronbach's Alpha, α
F1) Communication and Balance of Needs (Exchange of ideas / thoughts) Total items loaded = 6	13. Maintain regular communication with your family	2.76 (.86137) Mean near to 3, moderate need α = .896
	14. Need of regular communication with the person with cancer	
	19. To understand the experience/situation of the person with cancer	
	20. Balance your needs with the needs of the person with cancer	
	29. Having opportunities to participate in decision making on the treatment plans with cancer patient	
	15. Communicating to other caregiver(s)	
F2) Personal well- being (Spiritual, health, and emotion) Total Items loaded = 6	10. Look after your own health, including eating and sleeping properly	2.59 (.79164) α =.902
	25. Coping with the person with cancer's recovery not turning out the way you expected	
	27. Finding your spiritual beliefs	
	28. Finding the life meaning during the process of caregiving	
	30. The needs of belief/faith in the healing process	
	36. Learn how to cope with your emotion	
F3) Basic Healthcare and service (Services such as medical, counselling, or community support) Total items loaded = 7	9. Seek help in managing stress in the person with cancer	2.65 (.80909) α = .915
	6. Be involved in the person with cancer's care, together with the medical team	
	7. Have opportunities to discuss your concern with the healthcare providers on cancer	
	12. Get counselling service from the professional counsellor	
	5. Access community healthcare services when needed	
	8. Make sure complaints from the person with cancer's care are properly addressed	
	11. Adapt to the change of routine activities to cater to the needs of the patient	
F4) Access to information related to cancer and cancer care Total items loaded = 4	1. Accessing information relevant to your need as a caregiver	2.60 (.80015) α = .885
	2. Accessing information about the person with cancer's prognosis, or likely outcome (the outcomes of getting the illness)	
	3. Access information about support services for cancer caregivers	
	4. Access information on what the person with cancer's physical/emotional needs	
F5) Coping with change and fear of change Total items loaded = 3	23. Working through your feelings about death and dying	2.51 (.80573) α = .786
	24. Coping with others who do not acknowledge the change on your life as a result of caregiving	
	17. Address the feeling of fear of cancer may occur to other family member	
F6) Learning through online information and connection Total items = 3	34. Learn from online healthcare materials in making decision(s) for the person with cancer	2.26 (.79502) Lower mean, near to scale 2, which means lower need α = .822
	37. Seek information through social media site (eg Facebook, Twitter, Blog) about healthcare	
	38. Connecting with people via internet to learn about healthcare matters	

Notes: 1 denotes no need (either satisfy or non-applicable), 2 denotes low need, 3 denotes moderate need, and 4 denotes high need.