Exploring Caregivers' Perceived Stress with Their Need-Factors

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Abstract - **Caregivers face numerous challenges in providing care for a wide range of illnesses and health conditions associated with communicable diseases or non-communicable diseases. Pandemics, ageing populations, environmental health concerns, lifestyle changes, and other factors contribute to health issues, which lead to a greater demand for caregiving. This warrants further research on caregivers' wellbeing. The study reported six need-factor of caregivers, which are the needs for regular communications, personal well-being, basic healthcare, access to information, coping with change and learning about caregiving. This paper explores these objectives: 1) To determine perceived stress level of caregiving among the caregivers; 2) To determine perceived stress level of caregiving among caregivers based on gender, age, duration of caregiving, and frequency of using internet for information seeking; 3) To determine the relationship of the need-factors of caregivers with their perceived stress level. A total of 84 caregivers responded in a survey by using questionnaire. The t-test, analysis of variance, and correlation were used in data analysis. Findings reveal a normal distributed perceived stress level with a weak relationship with the need for information on caregiving. Caregivers should be able to access and acquire reliable information about the care guides which would aid in the provision and management of care, especially in this unprecedented time due to COVID-19.**

Keywords- Caregiver; perceived stress; information need; factor analysis; care model.

I. INTRODUCTION

The rise of noncommunicable diseases over the years has resulted in an increasing disease burden in our society, with people suffering from life-limiting chronic illnesses. Their debilitating illness necessitates the assistance of caregivers. As a result, there is a greater demand for caregivers to provide care informally or professionally. Caregivers frequently faced with a range of challenging circumstances that they must handle while doing their jobs, and stress becomes unavoidable for them. In a study published in Global Health 2020 Contribution 70025, Koo et al. [1] identified six need-factors that facilitate caregivers in carrying out their responsibilities and making care decisions. The six needs-factors are regular communications, personal well-being, basic healthcare, access to information, coping with change and learning about caregiving. In this study, the authors proceeded to determine if caregivers' perceived stress level of giving care influenced by these factors, particularly in a case study of cancer caregivers.

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" [26, 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]. If the caregiver is depressed or lacks resilience, the care recipient may not be able to get the most of care, thus affecting the quality of life for both parties. Support is needed for caregivers, such as physical, psychological, social, and spiritual [4][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 for them to perform their tasks is not well understood [24]; the roles of family caregivers are multifaceted and challenging. Health and social well-being have been an issue for the current society, hence care services (informal or formal) play an increasing role, and therefore the motivation of conducting this study.

Yuen et al. [26. p. 12] 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". They propose future research could examine various strategies in providing information to caregivers through eHealth modalities. Ribeiro et al. [18] suggested that innovative health education, such as mobile learning applications will further expand the context of a smart learning ecosystem for cancer education.

The objectives of this paper are as follows: 1) to determine perceived stress level of caregiving among the caregivers; 2) to determine perceived stress level of caregiving among caregivers based on gender, age, duration of caregiving, and frequency of using internet for information seeking; and 3) to determine the relationship of the need-factors of caregivers with their perceived stress level.

Section II reports relevant literature based on various aspect of caregiving, especially informal ones, and the challenges faced by caregivers. Section III reports the methods of the study which include the process of data reduction analysis using factor analysis. Section IV provides analysis and findings for the research questions. Section V is discussions based on findings and finally, Section VI is conclusion, and future works.

II. LITERATURE REVIEW

A. *Types of caregiver*

The need of caregiving in society is ever increasing. According to WHO’s Global Health Observatory [3] on a global scale, the life expectancy of a person is 73.3 years in 2019. For South-East Asia is 71.4 year; Europe being the highest, 78.2. Persons could expect a healthy life of 63.7 years. According to [3], the gap between healthy and unhealthy life is about 9 years, which the populations may need care services for that duration.

Generally, the relationship of informal caregiver and care recipient is family members relationships. Reference [7] reported that, 5.1% (95% CI = 4.45, 5.87) of adults (from the data of National Health and Morbidity Survey 2019 with 11,160 adults involved, estimated to represent 21.3 million adults aged 18 years and above) in Malaysia reported to be informal caregivers. [7] provided two levels of caregiving - high and low intensity. Those high ones were likely to be actively employed and provide longer duration of care compared to the low intensity ones. For low intensity caregiving, females, those aged 35–59 years, and those with long-term condition were more likely to have negative effects on health. For high intensity caregiving, caregivers aged 60 and over, those received training and those without assistance were more likely to have negative effects on health [7]; the research team further suggested that "caregiving, regardless of intensity, has a significant impact on caregivers" (p. 1). To reduce the negative effects of caregiving duties, all caregivers need some assistance from the supporting environments such as, the community and government to support their needs. [8] revealed that the issue of social care, particularly the role of informal caregivers and their wellbeing were often neglected or missing in the discussions. In the UK today, 6.5 million people are caregivers, to care for different type of care recipients including seriously ill persons. Providing care, especially long-term care, can impact on a person’s health, finance, and relationships [8]. Many caregivers provide care in long hours or many years which affect their wellness. The survey conducted by [8] reported that 25% of caregivers experienced bad or very bad physical health and 29% of them reporting bad or very bad mental health; 81% of all caregivers reported to have felt lonely or isolation. Since many countries are having a development of an ageing population, shrinking of family sizes, and increased of women participated in workforce has posted many challenges in social care.

B. *Framing caregiving based on triadic model*

There are some models related to caregiving. [10] has come up with a triadic model, namely Figure 1, which shows the factors influencing the three groups of stakeholders in caregiving. This paper highlighted the importance of caregiving has only recently been acknowledged by the nation, such as, the US, as an important topic to the nation.

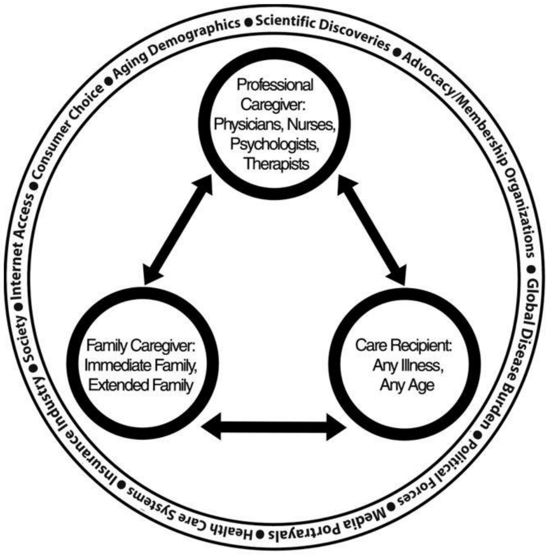


Figure 1. “A triadic model of caregiving: factors influencing the care recipient, family caregiver, and professional caregiver team” (Source: [10]).

Figure 1 shows that caregiver’s type/group is identified to be either a family caregiver or a professional caregiver. A family caregiver could be an immediate or extended family member. Care recipients can be inflicted with any illness, and at any age or age that requires care from others. Caregiving resides in the domain of public health. Figure 1 shows a care triad within a complex system of variables that influence the system of caregiving from a larger environment. The triadic is influenced by the complex force from societal, political, and scientific issues that shape the context of care, such as global disease burden, demographic changes, health insurance coverage, and scientific discoveries. Care triad deals with a variety of internal as well as external variables that facilitate or inhibit the care situation, enhancing the chances for success or hindering them. More studies should be conducted in understanding various factors influencing the wellbeing of caregivers, particularly the family caregivers.

C. Care model during COVID-19

Digital technology has transformed the care model in this unprecedented challenge time for healthcare systems internationally (the whole world) [11]. Caregiving during COVID-19 have affected the caregiver's burden and mental health [13]. Subsequently, this affected the parents and children relationship. Digital health transformation has been the rapid development and implementation of new models of care which incorporate digital technology health [11]. The forces to shield people from COVID-19 have resulted in an increased in information seeking using telemedicine consultation approaches, as well as the rapid rollout of digital apps, digital education / training, etc. Reference [11] concluded that the human costs of COVID-19 will be high and long remembered; the change of the use of new ways of remote and digital health and sustained these care models (extended even for caregiving) will be the future developments (p. 2).

D. Information technology for seamless learning and the infodemic phenomenon: A mixed blessing

The blessing for caregivers is that they are privileged in this era to receive healthcare information at their fingertips. The idea of a Seamless Learning Model in 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 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 [27][28][29]. 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. For catering the needs of receiving guidance, there are formal caregiving courses or websites created caregivers (such as, MOOC courses that promote lifelong learning). [14] proposed a Seamless Learning Framework as shown in Figure 2. It explains 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" [14, p.156], thus promoting seamlessness, with informal learning and information access at ones' 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).

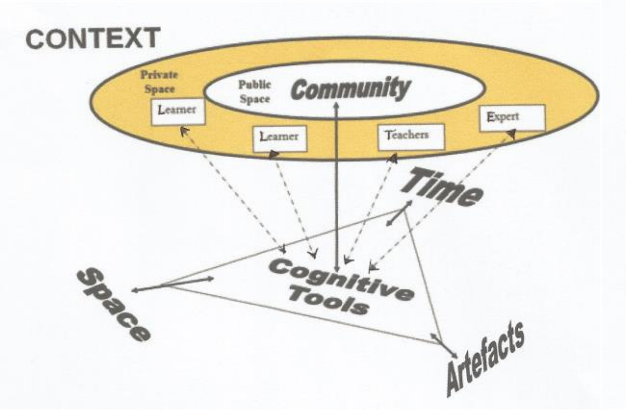


Figure 2. A Seamless Learning Framework [14].

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 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. [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, 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. Not a blessing part is the current infodemic. The Internet and social media are a 'mixed blessing' for the healthcare sector. However, the challenge will be to adhere to the legal framework that preserves the quality of the healthcare information provided on the internet and consume by the caregivers / patients. Infodemic challenges have even become a 'disastrous' than the pandemic itself. According to [15] that "…a global epidemic of misinformation—spreading rapidly through social media platforms and other outlets—poses a serious problem for public health". Fighting infodemic and misinformation is a joint effort. This is because fighting every outbreak will be accompanied with tsunami of information and misinformation, rumors, etc., and social media amplifying it [15]. Users, such as caregivers must critically analyze and select information posted on YouTube to make effective healthcare decisions. Moreover, diagnostic information online is sometimes used to confront doctors [12][15].

Consumption of online healthcare information and services is increasing [15] and has empowered caregivers (and patients) to enhance their health and digital literacy for improved decision-making [9]. Hence, getting more insights on the proper way of obtaining useful and informative inputs for caregivers is essential.

E. Identifying challenges and needs of an informal caregiver

Among the bigger challenges faced in long term caregiving are the need to give up their personal life or career and becoming a full-time caregiver, this is normally a case for Asian culture [16]. Most caregivers will be coming from family members who are informal mostly, and conflict may happen between them with care recipients or the other family members who are not able to empathize the roles and feeling of caregivers. Another challenge that they faced, is the 'shrink' of social life to be just in the circle of family and a gradual distant from their career life [16].

Seattle Cancer Care Alliance (SCCA) [19] listed the challenges of caregiving such as, 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. 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 specialists. Chen [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. Girgis et al. [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. Caregivers with anxiety and depression were more likely to report, "at least one unmet moderate or high need in comparison to non-anxious participants"; younger caregivers faced at least one unmet moderate or high need around "psychological and emotional", and "work and social", as compared to the older participants. Girgis et al. [6] suggested the findings can be used to prioritize healthcare resources and tailor supportive cancer care service accordingly. The model and framework reviewed above facilitated the conception of need-factors as reported by [1].

This study focuses on investigating significant factors that correlate to caregivers' perceived stress levels. The contributing constructs provide guidelines on further plans or actions to reduce stress among caregivers. Cancer caregivers were chosen as the study's setting due to the rising number of cancer patients in Malaysia [21] and the need for improving cancer management, which certainly requires greater focus in research, such as, on the caregiving aspect.

III. METHODS

A survey was conducted in a hospital with two cancer specialist clinics run by National Cancer Society Malaysia (NCSM), an NGO for cancer awareness and cancer care. Permission was granted from NCSM 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.

A. Instrument

The instrument of the survey was adapted from [6] to study needs of accessing information 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 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. A comprehensive factor analysis was conducted to establish the factors. The items were analyzed in a comprehensive factor analysis. It involves two stages as below.

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, value of KMO should be larger than 0.5 for achieving condition of satisfactory.

On the other hand, the Barlett's 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 Barlett's 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 BARLETT'S TEST

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

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 3). Other components have lower value of eigenvalue, which will not be considered for the next step.

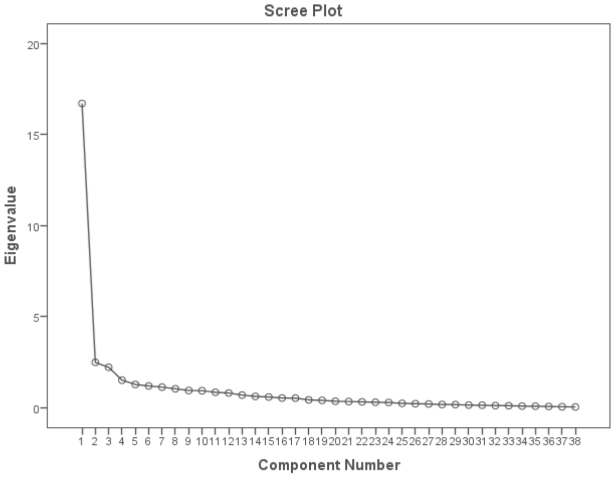


Figure 3. Scree plot showing the elbow at the point of the sixth component at the value of Eigenvalue >= 1.

The six components which have eigenvalues more than one (namely 16.714, 2.483, 2.211, 1.504, 1.270, 1.187 as observed in the analysis of the total variance explained by components) indicate there are six factors or constructs in the extraction process.

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 Viramax 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. 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 indicates 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 2 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 2. 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
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
26		*0.546*			*0.448*				0.098 (<0.2)	Item 26 is dropped
9			0.656							
6			0.605							
7			0.54							
33	*0.411*		*0.518*			*0.426*			0.015 (<0.2)	Item 33 is dropped
32			*0.515*		*0.486*		*0.432*		0.054 (<0.2)	Item 32 is dropped
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
22								0.624		

16	*0.418*	*0.5*	0.082 (<0.2)	Item 16 is dropped

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 2 is a matrix table showing 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'.

B. *Results of the Factor Analysis*

The needs-factors are identified as F1-F6 and are detailed as follows:

- 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.

The items were analyzed using factor analysis. Factors on the needs of cancer caregivers were then identified in the analysis (This part of analysis was reported in [1]). The instrument also collected data of profiles, caregiving experiences and online activities behavior, caregivers' perceived stress level. The instrument also measures the perceived stress level of caregivers according to a scale of 1 - 10. Respondents were freely to mark their level of stress guided by the simple semantic such as, minimal stress, some stress and higher stress (in which data is gathered from a scale bar from 1 to 10, where 1 represents minimal stress, the middle scale represents some stress and 10 represents the higher stress (Refer to Figure 4)

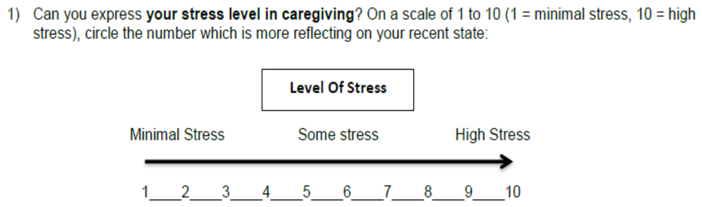

1) Can you express **your stress level in caregiving**? On a scale of 1 to 10 (1 = minimal stress, 10 = high stress), circle the number which is more reflecting on your recent state:

Figure 4. Scale of perceived stress level.

C. *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

Two parts of analysis were conducted, firstly is Part A - demographic information and perceived stressed level, and Part B - probing caregivers' profile such as, age, gender, duration of caregiving, frequency to be online for accessing information, and the six need-factors with perceived stress level among the group of caregivers.

D. *Description of the demographic information*

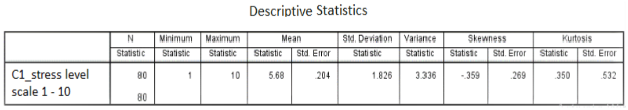
The total participants were 84. More than half were females, most of them were Chinese (83%) with their religion Buddhism or Taoism, middle income or lower (77%), holding diploma and above (59%), aged more than 30 years old (73%). More than half of them (62%) have been caregiving for 6 months and above, 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.

Profile of caregivers, especially their age, gender, duration, and frequency of online access to information are further examined, whether these variables influence caregivers' stress levels.

RQ1 – What are the caregivers' stress levels?

Figure 5 presents the distribution caregivers' stress levels. The bell shape of the distribution depicts the data is normally distributed. Further testing of normality is conducted by calculating the Z-score. The Z-score value (as shown below) is calculated from the skewness statistic (skewness statistic= -0.359) and standard error (standard error = -0.269) of it (refer to Table 3).

TABLE 3. STATISTIC AND STANDARD ERROR FOR THE CALCULATION OF Z-SCORE



Descriptive Statistics

	N	Minimum	Maximum	Mean		Std. Deviation	Variance	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
C1_stress level scale 1 - 10	80 80	1	10	5.68	.204	1.826	3.336	-.359	.269	.350	.532

Z-score = skewness statistic/ standard error= -0.359/-0.269 = -1.386

The Z-score = -1.386 is located between –3.29 and +3.29 shows a fulfilment of requirement of normality. It is indicated the medium sample size (50< n < 300), a threshold value of Z score is 3.29 to determine the distribution of data is normal. In this case, the null hypothesis (H0: the data is not distributed normally) is rejected at alpha level of 0.05. Hence, the data is distributed normally. In addition, the data satisfies normality since the ratio of standard error (-0.269) to its standard error is in between -2 and +2.

Refer to Figure 5, overall, the caregivers were averagely stressed on their caregiving task, with most of them having middle stressed level ranging at the mean value of 5.68 (Std. Dev. = 1.826). Majority of them have some stress (within the range of scale of 4 – 8), i.e., some stress in caregiving. The distribution of stress level is showing a normal distribution (Figure 5).

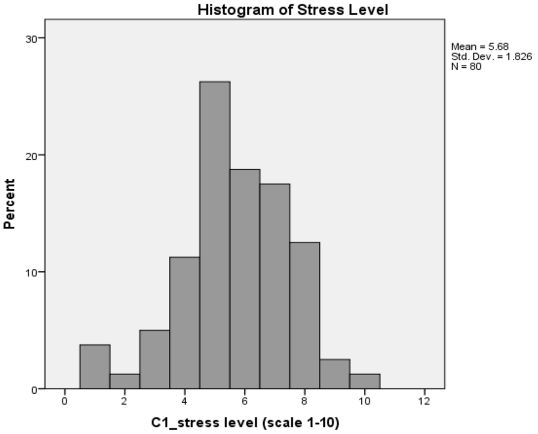


Figure 5. Histogram of perceived stressed level.
*Scale for perceived level is 1 – 10. * Note: 4 missing values reported.*

RQ2: Is there any difference in perceived stress level between/among the grouping variables (namely gender, age, period of caregiving, frequency of using internet for information seeking)?

Table 4 shows descriptive data for four grouping variables. The t-statistic and F-statistic are referred to examine whether the grouping variables has an influence on perceived stress level. The findings show that the perceived stress level does not shows difference between/ among each of the grouping variables (in Table 4) since all the p-values of the statistical test (t-test and ANOVA) exceed 0.5. Thus, it has sufficient evidence that there are no differences in perceived stress level among different groups (gender, age, period of caregiving, frequency of using internet for information seeking) of caregivers.

TABLE 4. COMPARING DEMOGRAPHIC AND EXPERIENCE VARIABLES WITH PERCEIVED STRESS LEVELS

Grouping Variables	**Mean (Std. Dev.)**	**Statistical Test**	**P value**
Main measure	Perceived Stress Level		
Gender		t = 1.122	0.265 (not significant)
Male	5.94 (1.722)	(df = 78)	
Female	5.48(1.894)		
Age			0.184
< 30	5.21(1.865)	F = 1.734	
30-49	6.09(1.505)		
50-69	5.50 (2.259)		
Duration/Period of caregiving			
<0.5 year	6.04 (1.503)	F = 1.302	0.281
0.5 year-1 year	5.43 (2.507)		
1– 2 year	5.71 (1.978)		
>2 year	5.00 (2.000)		
Frequency of using internet for information seeking:-			
Very frequently (everyday and almost everyday)	5.54 (1.584)	F = 1.6695	.176
Weekly, fortnightly or seldom	5.88 (2.748)		
Never	6.69 (1.653)		

Note: The dependent variable is caregivers' perceived stress level.

RQ3: Is there any relationship between caregivers' need factors with their perceived stressed on caregiving?

Table 5 shows the correlations of Perceived Stressed Scale with the six need-factor identified in [1], where the bivariate correlation coefficient values are displayed with the indication of p-value. The findings show that the need for 'access to information', 'basic healthcare' and 'personal wellbeing' are among the significant factor that correlate positively (have positive relationships) with perceived stress level since the p-values are less than 0.05. The correlation coefficient for the one variable which is the need for accessing information is the highest (r=0.341, p-value < 0.05) among these variables. Another three need-factor (regular communication need, need to cope with change, and the need for learning through online information and connection) were not correlated with perceived stress.

TABLE 5. CORRELATIONS BETWEEN CAREGIVERS' NEED FACTORS WITH THEIR PERCEIVED STRESS ON CAREGIVING

Need-factor (with reference to [1])	Correlation Coefficient, r	p value Sig. (2-tailed)
F1_Communication	0.193	.087
F2_Personal wellbeing	0.221	.049*

F3_Basic healthcare	0.317	.004*
F4_Access to info	0.341	.004**
F5_Cope with change	0.179	.112
F6_Learning through online	0.173	.126

Correlation of six need-factor with perceived stress; n = 84

V. DISCUSSION

The need for basic healthcare, personal wellbeing and information access are the three crucial factors which have some correlations with caregivers' perceived stress level. The personal wellbeing (in the form of positive feeling, counseling, spiritual) has often been neglected in modern care model. Personal wellbeing and the access for the basic healthcare for caregivers is vital for stress relief and to build a more robust and holistic model for patient care system. The number of caregivers is increasing due to the unprecedented pandemic situations.

The information seeking behaviors (push and pull for information) is now seamlessly a part of the life for caregivers. The information areas can be referred to online or offline channel. The infodemic viral or fake news are also a key challenge for everyone, especially more critical for those with low literacy in digital skills and health knowledge. The findings have shown that, information access to caregivers on appropriate information on healthcare, caregiving, etc. has a stronger relationship to perceived stress. This was also evidenced in the descriptive findings (mean and standard deviation) of the group of caregivers who never access information via internet to be higher stress compared to other group of users.

The seamless learning concepts by [14] are adapted to suit the needs for caregivers and keeping them informed and empowered while at the same time learning to acquire skills and knowledge for their caregiving tasks from various resources and people. Keeping caregivers well-informed and information-literate is vital in this age. In recent years, the rapid shift of digital technologies has put a toll on caregivers, particularly those who are health-illiterate and would not know how and where to acquire information as technology advanced. Most information is sought online these days. Those who never online due to many reasons (illiterate, no access to mobile data or devices, etc.) had reported higher stress level. Caregivers should be provided training or education on information seeking skills, digital and health literacy skills. They will be more empower when dealing with the new world of information era.

The current study and analysis finding is also aligned with [6] which reported that, "more caregivers experienced unmet needs varied across cancer types for the Health Care Service Needs and Information Needs domain." The unmet needs may result uneasiness in caregiving across cancer types, and these two factors contributing to some stress. [6] further stressed that by experiencing any one of the factors, "even if just one unmet need, can be quite distressing". [2] explained that caregiving needs for information is not as simple as we thought. There are these information needs related to these areas: treatment, dietary, disease specific information, homecare, psychological support, health, insurance and social welfare and funeral arrangement. These categories of information are complex, demanding, and unfamiliar to many caregivers, could be unmanaged by just one or solely one caregiver.

Information to guide new family caregivers can be provided early by healthcare bodies which can reduce the anxiety and uncertainty exhibited by caregivers [2].

A. Limitations

The study has sampling limitations, the caregivers are mostly from one ethnicity and the number of respondents is less than 85. The convenience sample for this study comes from one hospital. The sample of the study are caregivers who were selected purposively from cancer clinics in a hospital, they were affected by different kinds of cancer. All these limitations are acknowledged. Future research is proposed to incorporate more participating hospitals and caregivers.

VI. CONCLUSION AND FUTURE WORK

Overall, the caregivers involved in this study perceived that they have some stress with a few said they have minimal stress or higher stress.

Future directions of this research will consider studying on one or two aspects of need factors, especially on the needs for information during caregiving by informal caregivers. Interaction and communication of family members and decision-making processes are all quite relevant or maybe different at different stages of caregiving.

Future research will consider the different duties of caregivers and the level of quality of treatment received by patients. These variables may influence the requirements of needs by caregivers and subsequently affecting the quality of care provided by them, especially to their loved ones. [23] proposed an urgent need for research directions on the impact of COVID-19. Among the highlighted directions are the general issues with special considerations, i.e., role of technology as the 'oxygen' (as vital medium), and the importance of contextualization of research. [2] stressed about the culture aspect in caregiving; the influence of culture in health information studies requires further research. This understanding will move toward better ways of living and coping with COVID-19. Although caregiving is a routine task, it is however, a very challenging task with stress and emotion. Ethnographic method for this research area can be used to enhance understanding of the information-seeking behavior of family members.

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REFERENCES

[1] A. C. Koo et al., “Cancer caregivers’ needs for their well-being in information era,” The Ninth International Conference on Global Health 2020 Contribution 70025, 25-29 October, 2020, pp. 9-12.

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

[3] WHO, “Global health observatory data repository: Life expectancy and healthy life expectancy,” World Health Organization,2020. https://apps.who.int/gho/data/view.main-searo.SDG2016LEXREGv?lang=en%0Ahttp://apps.who.int/gho/data/view.main.SDG2016LEXREGv?lang=en [retrieved: August, 2021].

[4] 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 [retrieved: September, 2021].

[5] J. Li et al., “Communication needs of cancer patients and/or caregivers: A critical literature review,” Journal of Oncology, vol. 2020, Article ID 7432849, pp. 1-12.

[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), 2011, pp. 387–393.

[7] S. Jawahir, E. H. Tan, Y. R. Tan, S. N. Mohd Noh, and I. Ab Rahim, “The impacts of caregiving intensity on informal caregivers in Malaysia: findings from a national survey,” BMC Health Serv. Res., vol. 21, no. 1, 2021, pp. 1-16.

[8] Carers, U. K. "State of caring: A snapshot of unpaid care in the UK." State of Caring Report, London, 2019.

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

[10] R. C. Talley and J. E. Crews, “Framing the public health of caregiving,” American Journal of Public Health, vol. 97, no. 2. 2007, pp. 224–228, doi: 10.2105/AJPH.2004.059337.

[11] T. Robbins et al., “COVID-19: A new digital dawn?,” Digit. Heal., vol. 6, 2020, pp. 1-3.

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

[13] B. S. Russell, M. Hutchison, R. Tambling, A. J. Tomkunas, and A. L. Horton, “Initial challenges of caregiving during COVID-19: Caregiver burden, mental health, and the parent–child relationship,” Child Psychiatry & Human Development, 51(5), 2020, pp. 671-682.

[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), 2010, pp. 154–169.

[15] J. Zarocostas, “How to fight an infodemic,” Lancet, vol. 395, no. 10225, 2020, p. 676.

[16] S. H. Tey, “Long term caring journey: How to comfortably be yourself?” [translated from Chinese] AiFM, July 12, 2021.https://web.facebook.com/watch/live/?v=1162201980960056&ref=watch_permalink [retrieved: August, 2021].

[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), 2013, pp. 2029–2032.

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

[19] Seattle Cancer Care Alliance, “Caregiver companion guide,” 2018. https://www.seattlecca.org/sites/default/files/inline-files/Caregiver%20Guide_1.pdf [retrieved: November, 2021].

[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, no. 12, 2014, pp. 5063–5069.

[21] WHO, “Cancer country profile 2020: Malaysia burden of cancer,” 2020. https://www.who.int/cancer/country-profiles/MYS_2020.pdf [retrieved: October, 2021].

[22] A. B. Sullivan and D. Miller, “Who is taking care of the caregiver?”, Journal of Patient Experience, vol. 2(1), 2015, pp. 7–12.

[23] V. Venkatesh, “Impacts of COVID-19: A research agenda to support people in their fight,” Int. J. Inf. Manage., vol. 2020, no. 55, 2020, pp. 1–6.

[24 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, vol. 25, no. 2, 2016, pp. 294-306.

[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, no. 1, 2015, pp. 3–9.

[26] 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, vol. 26, no. 2, 2018, pp. e191- e206.

[27] Cancer.Net Website https://www.cancer.net/ [retrieved: August, 2020].

[28] Skill For Care Website https://www.skillsforcare.org.uk/About/About-us.aspx [retrieved: August, 2021].

[29] Dignity In Care Website. https://www.dignityincare.org.uk/About/ [retrieved: August, 2021].