ORIGINAL ARTICLE

Loneliness among Caregivers of Children with Life Limiting Conditions in Kelantan: Its Correlation with Life Satisfaction

Fairuz Iylia' Nadhirah Mohd Maidin[1,2], Fahisham Taib[1,2], Mohamad Ikram Ilias[1,2], Shamini Subramaniam[1,2], Nurul Jannah Ambak[1,2]

[1] Department of Paediatrics, School of Medical Sciences, Universiti Sains Malaysia, 16150 Kubang Kerian, Kelantan, Malaysia.
[2] Hospital Universiti Sains Malaysia, Health Campus, Universiti Sains Malaysia, 16150 Kubang Kerian Kelantan, Malaysia.

ABSTRACT

Introduction: Loneliness among caregivers is common. This study examined loneliness and life satisfaction among caregivers of children with LLI and its associated factors. **Materials and methods:** This cross-sectional study utilized the validated Malay questionnaires UCLA Loneliness Scale and The Satisfaction with Life Scale to measure loneliness and life satisfaction level among caregivers of children with LLI in Kelantan. The data were collected from April to September of 2023. Descriptive statistics were used to analyze socio demographic patterns, Pearson's correlation was used for the relationship between loneliness and life satisfaction, while associations were investigated using linear regression analysis. **Results:** Out of the 335 informal caregivers, 271 were recruited from the Paediatric Clinic and 64 from home visits. Majority of respondents were Malay (94.9%), married (89.6%), unemployed (61.5%) with secondary education (51.9%). Their average household income was RM 2,614.27 (SD = RM 2,592.98). The mean level of loneliness among caregivers was 17.0 (SD = 5.4), with most reported moderate to high level (34.0%) of loneliness. The mean level of life satisfaction was 23.7 (SD = 6.7), with less than 10% had a low life satisfaction level. No significant correlation between loneliness and life satisfaction (p-value = 0.507). However, employment status and family relationships were found to have a significant association with loneliness. **Conclusion:** There was no correlation between loneliness and life satisfaction among caregivers of children with LLI in Kelantan. Factors such as jobs and kinships are an important association.
Malaysian Journal of Medicine and Health Sciences (2025) 21(5): 150-157. doi:10.47836/mjmhs.21.5.19

Keywords: Loneliness, Caregivers, Children, Life-limiting conditions, Life satisfaction

Corresponding Author:
Fahisham bin Taib, FRCPCH
Email: fahisham@usm.my
Tel : +6097676519

INTRODUCTION

Loneliness is a persistent and chronic feeling of social isolation or a lack of meaningful connections with others. More specifically, loneliness refers to an unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively (1). That feeling can alleviate or remain constant across the life course because the level of loneliness depends on the personality, situation and condition of that individual. Being unable to connect with appropriate support systems, such as friends, family, or social groups, has been proven to be detrimental to physical well-being, which then has the potential to worsen physical ailments and ultimately impact life expectancy (2). In Malaysia, a study by Abu Bakar, et al. has highlighted the negative impacts of caregiving responsibilities on caregivers' emotional, financial, social, and physical well-being (3). The experience of loneliness is common among caregivers, especially those who are caring for their loved ones with chronic or life-limiting illnesses (LLI). With the advancement in medicine, there are higher numbers of surviving patients with chronic medical illnesses than before but with more disabilities and complications. Previous study in Japan found that informal caregivers were two times more likely to experience loneliness compared to non-caregivers (4). Individual caregivers have to bear multiple responsibilities including provision of physical, emotional and financial resources at the expense of their own health, and psychological well-being (5).

Satisfaction with life is the mental process of evaluating one's life based on a specific standard criterion and is viewed as a crucial component of subjective well-being. Family is still the backbone of society in most ASEAN countries, especially in Malaysia. Having a child with LLI will not only require special attention to specific patient's needs but also to the whole family members physically, socially and emotionally. Most of the caregivers' needs are ignored and overlooked. Some caregivers experience additional physical strains,

emotional tolls, social difficulties and financial pressure which can substantially lead to loneliness and poor life satisfaction.

Several studies evaluating the impact of children's chronic morbidity and disability on the family have shown the presence of negative outcomes. Problems identified include social stigma, altered family dynamics, emotional disturbance (6), and psychosocial impacts (7). There are variations in patient's characteristics, family structure and service availability for disabled and LLI patients in Malaysia compared to the West; as such, the impact on the families may differ in nature and magnitude.

LLI refers to a group of medical conditions that significantly reduce a person's life expectancy and have a profound impact on their quality of life. These can be genetic disorders, congenital abnormalities, cancers, and neurodegenerative diseases. In paediatric age groups, there are a wide range of life-limiting and life-threatening conditions, which can be categorized broadly into four based on agreeable criteria and diagnosis in the RCPCH/ ACT grouping (8). There are several examples of LLI in the paediatric population that are commonly seen, for example, complex congenital heart disease, cerebral palsy, muscular dystrophy, and advanced leukaemia. "Directory of Life Limiting Conditions" has been created to list the number of LLI in children (9). The directory consists of nearly four hundred ICD-10 codes associated with diseases that can limit the life of children. The classification of a condition as "life limiting" means that its trajectory can plausibly be described by at least one of the archetypes set out in the RCPCH/ACT 1997 guidelines. The prognosis for the children with LLI varies depending on the specific conditions and individual factors. It is important for individuals facing such illnesses to receive appropriate medical care, support and as well as steps to improve their overall wellbeing. These children often require extensive medical care, including frequent hospitalizations, surgeries and various treatments.

In Malaysia, studies on loneliness are very limited. Loneliness is probably prevalent because of the emotions woven into the lives of these caregivers, especially those caring for children with LLI. It is crucially important to study this, to understand the knowledge gap and explore factors that could lead to loneliness in life.

The objective of this study is to explore the level of loneliness and life satisfaction among the caregivers of children with life limiting conditions in Kelantan, using the validated Malay version of questionnaires (10,11). Recognizing and addressing these impacts on caregivers especially in terms of psychological impact and life satisfaction are crucial to plan for a comprehensive care to their respective family members. Screening of caregivers will help for an earlier detection and necessary and timely interventions.

Operational Definition

Loneliness is defined as an unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively (1). On the other hand, life satisfaction is defined as a cognitive, global appraisal that people make when considering their contentment with their life as a whole or with regard to specific domains of life such as family, environment, friends and themselves (12). According to Schoenmakers, caregiver is a person who, for evident reasons and on a regular basis, provides care for a care-demanding person, in his/her immediate environment and who is not part of a formal or professional organization (13). In this study, main caregivers and those who are mostly involved in taking care of the child with LLI. A LLI is an illness that can be reasonably expected to cause the death of the individual within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses that are expected to shorten an individual's life (14). According to RCPCH/ACT 4 subcategories have been identified (8). Category 1 are the illnesses that include advanced cancers, complex congenital heart diseases, and others for which treatment may be feasible but can also fail. While disorders like HIV infection, cystic fibrosis, or chronic respiratory and severe immunodeficiencies fall under Category 2. These are conditions where premature death is inevitable, but patients may live long to participate in normal activities. Category 3 refers to progressive illnesses without curative treatment options, where treatment is exclusively palliative and commonly extends over many years such as metabolic diseases or syndromic disorders. Conditions in Category 4 include those that have irreversible but not progressing conditions and they are at risk of dying young due to complications, such as severe cerebral palsy with recurrent infections or severe neurologic sequelae of infective diseases or congenital brain abnormalities.

MATERIALS AND METHODS

A cross-sectional study was done from 1st April 2023 until 30 September 2023 using the two comprehensively validated Malay version questionnaires. These instruments comprised of sociodemographic information and specific questions adapted from UCLA Loneliness Scale (ULS-8) and Satisfaction with Life Scale (SWLS). The latter two instruments are designed to measure the level of loneliness and satisfaction with life respectively (10,11). The caregivers were those who have children with LLI attending paediatric outpatient at Hospital USM or under registration of Homecare team (YOKUK Homecare). The homecare is a collaborative partner between Hospital USM and a private non-governmental organization, which function to provide palliative care support in the community. The study has received approval from the Human Research Ethics Committee

of the Medical School of HUSM (Protocol code: USM/JEPeM/22090629).

Participants

Participants were recruited through convenience sampling. They were identified during registration or before the home visits by YOKUK Homecare teams respectively. The total sample size calculated was three hundred seventy-two based on the study by Bonin-Guillaume et al (15).

The inclusion criteria were informal caregivers of children with LLI as defined by RCPCH/ACT grouping who had cared for the patient for more than 3 months. The caregivers must be 18 years old or older and the patients under their care were aged between 3 months to 18 years old at the time of data collection. Those who were unable to read or understand Malay or English language, and formal caregivers such as paid caregivers were excluded from this study.

Subject Recruitment

There were two hundred seventy-one participants recruited from Paediatric clinic, Hospital USM and the remaining sixty-four participants were from YOKUK Homecare. Participants were identified based on the fulfilled inclusion criteria and individual code numbers were assigned. Questionnaires were distributed to the consented caregivers prior to medical consultation. Informed consent was obtained in-person after thorough explanation of the study. Participants were given adequate time to complete the questionnaires before participants left the clinic or the home visit session ended. The honorarium was given to the participants as a token of appreciation.

Research tool

The questionnaire would take approximately 30 minutes to complete. The first section included the demographic profile of the participants while the second and third parts were the instruments related to the UCLA Loneliness Scale (ULS-8) and the Satisfaction with Life Scale (SWLS) questions as the main research tools. ULS-8 measures the level of loneliness. It contains eight items selected from the revised ULS by Hays and DiMatteo in 1987. Items were rated on a 4-point scale (1 never, 4 always) and two items were reverse-coded prior to analysis. The SWLS, which consisted of five items, was used to measure the subjective well-being of the participants. The score of SWLS was determined via a seven-point scale that measured global cognitive judgments of one's life satisfaction. The level of life satisfaction of caregivers was decided based on the sum up of total scores on each item. Both ULS-8 and SWLS studies were validated among Malaysians participants by Swami, 2009 (10) and Swami, et al 2009 (11) respectively, with good Cronbach alpha values. Permission to apply the questionnaires in this study from the original author was obtained beforehand.

Statistical Analysis

The data were analysed using IBM Statistical Package for Social Science (SPSS) version 27. Descriptive statistics analysis was used to present the sociodemographic patterns, level of loneliness and life satisfaction. The categorical data were reported as frequencies and percentages while numerical data were reported as mean and standard deviation. Pearson's correlation analysis was applied to study the correlation between loneliness and life satisfaction. A p-value < 0.05 was considered statistically significant.

Simple and multiple linear regression were employed to analyse the associated factors that contribute to loneliness. Factors with p-value of less than 0.25 (p-value<0.25) were selected and entered multiple linear regression. Stepwise, forward and backward methods were applied. The results were presented as crude β (95% Cl) and adjusted crude β (95% Cl). For the final model, factors with a p-value <0.05 were chosen as statistically significant.

RESULTS

Sociodemographic Data

Caregiver's profile

Three hundred thirty-five caregivers agreed to participate in completing the questionnaires. The mean age of caregivers was 40.0 years old (SD = 7.7). The majority of them were female (83.0%), Malay (94.9%), married (89.6%), had completed secondary education (51.9%), and were unemployed (61.5%) with a mean household income of RM 2614.27 (SD = RM 2592.98). Most of them were mothers of the child with LLI (80.0%) who were healthy (87.8%) and stayed together with other family members or relatives (96.7%) with a mean of 3.87 (SD = 1.76) family members under their care and 1.11 (SD = 0.36) patients under their care. Caregivers reported various challenges following the child's diagnosis, including social constraints (37.0%) and financial constraints (29.9%). The common actions to combat their loneliness included socializing (37.0%) and doing part-time work (29.6%), while leading a healthy lifestyle (37.0%) and raising family income (29.9%) were the strategies to achieve their life satisfaction. Table I summarized the sociodemographic characteristics of the caregivers.

Table I: Social demographic characteristic of the caregivers (n = 335)

Variable	n (%)	Mean (SD)
Age (year)		40.0 (7.7)
Gender		
Male	57 (17.0%)	
Female	278 (83.0%)	
Ethnicity		
Malay	318 (94.9%)	
Non-Malay	17 (5.1%)	
Marital Status		
Single	2(0.6%)	
Married	300(89.6%)	
Divorced	33(9.9%)	
Education level		
No formal education	2(0.6%)	
Primary	15(4.5%)	
Secondary	174(51.9%)	
Tertiary	144(43.0%)	
Employment Status		
Employed	126(37.6%)	
Unemployed	206(61.5%)	
Retired	3(0.9%)	
Household Income (RM)		2614.27(2592.98)
Relationship With Patient		
Mother	268(80.0%)	
Father	53(15.8%)	
Relatives	14(4.2%)	
Caregiver's Health status		
Unwell	41(12.2%)	
Well	294(87.8%)	
Live alone		
Yes	11(3.3%)	
No	324(96.7%)	
Number of family members under caregivers' care		3.87(1.76)
Number of patients under caregivers' care		1.11(0.36)
Challenges in caregiver's life		
Social constraints	124(37.0%)	
Financial constraints	100(29.9%)	
Psychological changes	53(15.8%)	
No changes	58(17.3%)	
How caregivers dealing with loneliness		
Socialize and leisure	124(37.0%)	
Do part time job	99(29.6%)	
Positive thinking	58(17.3%)	
Supportive group	54(16.1%)	
How caregivers achieve the life satisfaction		
Practice a healthy lifestyle	124(37.0%)	
Increase family income	100(29.9%)	
Take good care of patients	58(17.3%)	
Sharing experiences and problems	53(15.8%)	

SD = standard deviation

Patient's profile

Table II illustrates the social demographics of the children with LLI under caregivers' care. The mean age of the children with LLI was 8.0 years old (SD =5.03). Majority of them have fallen under Category 4 conditions (40.6%), with Category 1 (31.6%), Category 2 (19.7%), and Category 3 (8.1%) following in order of prevalence. These categories represent different specific diagnoses within the spectrum of LLI according to the RCPCH/ACT classification. The mean duration of care reported by their respective caregiver is 6.82 years (SD = 4.84).

Table II: Social demographic characteristics of the children with LLI under caregiver's care (n = 335)

Variable	n (%)	Mean (SD)
Age (year)		8.0(5.03)
LLI Types according to RCPCH ACT archetype		
Category 1	106(31.6%)	
Category 2	66(19.7%)	
Category 3	27(8.1%)	
Category 4	136(40.6%)	
Duration of care (years)		6.82(4.84)

SD = standard deviation

Loneliness and Life Satisfaction

The highest mean score of loneliness among caregivers of children with LLI was 17.0 (SD = 5.4) and the majority of them had moderate to high levels of loneliness (34.0%). A smaller percentage reported low levels of loneliness (30.4%), while only a minority of them showed high levels of loneliness (3.6%). Meanwhile, the average score for life satisfaction among caregivers of children with LLI was 23.7 (SD = 6.7). More than a third (34.0%) of them showed slightly life satisfaction and only 0.95% of caregivers have extreme life dissatisfaction. Summary of the loneliness and life satisfaction levels of the caregivers is shown in Table III.

Table III: Level of Loneliness and Life Satisfaction among caregivers of Children with LLI (n = 335)

Variable	n (%)	Mean (SD)
Loneliness		17.0(5.4)
Low	102(30.4%)	
Normal to moderate	107(31.9%)	
Moderate to high	114(34.0%)	
High	12(3.6%)	
Life Satisfaction		23.7(6.7)
Extremely dissatisfied	3(0.95%)	
Dissatisfied	29(8.7%)	
Slightly dissatisfied	56(16.75)	
Neutral	14(4.2%)	
Slightly satisfied	114(34.0%)	
Satisfied	64(19.1%)	
Extremely satisfied	55(16.4%)	

SD = standard deviation.

Correlation between Loneliness and Life Satisfaction

Loneliness had no significant correlation with life satisfaction among the caregivers of children with LLI in Kelantan with (r = -0.036) and p-value of 0.507.

Factors Associated with Loneliness

Regression analysis has identified two factors to have a significant association with the level of loneliness among the caregivers. These factors were employment status ($p < 0.001$) and the relationship of caregivers with patients ($p = 0.022$). Being employed is associated with a decrease in the level of loneliness 2.5 times compared to the unemployed individuals. This study also suggests that a certain type of caregiver relationship (child's mother) is associated with a decrease in the level of loneliness by 3.3 times compared to the reference group who was a relative. These factors were summarized in Table IV.

Table IV: Simple and multiple linear regression analysis of the factors that contribute to the level of loneliness among the caregivers (n = 335)

Variable	Simple Linear Regression			Multiple Linear Regression [c]		
	b(SE) [a]	95%CI	p-value	Adj b(SE)[b]	95%CI	p- value
Gender						
Male	Reference					
Female	-0.39 (0.78)	(-1.93,1.14)	0.615			
Age (years)	0.01 (0.04)	(-0.07,0.08)	0.797			
Ethnicity						
Malay	Reference					
Non-Malay	4.60(1.31)	(2.02,7.19)	<0.001			
Educational Level						
No formal education	Reference					
Primary	-4.50 (4.04)	(-12.46,3.46)	0.267			
Secondary	-4.72(3.82)	(-12.23,2.80)	0.218			
Tertiary	-4.20(3.83)	(-11.73,3.23)	0.273			
Marital Status						
Single	Reference					
Married	5.08(3.81)	(-2.41,12.57)	0.183			
Separated	5.03(3.91)	(-2.66,12.72)	0.199			
Employment Status						
Unemployed	Reference					
Employed	-1.85(0.60)	(-3.03, -0.07)	0.002	-2.55(0.71)	(-3.95, -1.16)	<0.001
Retired	-2.76(3.08)	(-8.84,3.30)	0.371	-3.74(3.12)	(-9.88, 2.40)	0.232
Household Income (RM)	0.00(0.00)	(-0.001, 0)	< 0.001			
Relationship with patient						
Relative	Reference					
Mother	-2.89(1.47)	(-5.78, -0.01)	0.049	-3.31(1.45)	(-6.16, -0.47)	0.022
Father	-3.16(1.61)	(-6.32,0.002)	0.050	-1.66(1.63)	(-4.87,1.56)	0.311
Caregiver's Health status						
Unwell	Reference					
Well	-1.44(0.89)	(-3.19, 0.32)	0.108			
Live alone						
No	Reference					
Yes	-2.58(1.64)	(-5.81, 0.65)	0.117			
Number of family members under caregiver care	-0.52(0.15)	(-0.81, -0.23)	<0.001			
Number of patients under caregiver care	-0.53(0.81)	(-2.12,1.06)	0.510			
LLI types						
Category 1	Reference					
Category 2	-0.30(0.84)	(-1.96,1.36)	0.720			
Category 3	0.78(1.16)	(-1.51, 3.06)	0.504			
Category 4	0.78(-0.01)	(-1.46, 1.28)	0.897			
Duration of care	-0.08(0.06)	(-0.19,0.04)	0.214			

Factors with P-value < 0.25 were selected for multiple linear regression Backward LR Multiple Linear models was applied
[a]: Crude regression coefficient (standard error)
[b]: Adjusted regression coefficient
[c]: Multiple linear regression ($R^2 = 0.051$, no interaction between independent variable and no multicollinearity was found)
R: with the two significant variables, the model explains 5% of variation in the loneliness level in the study sample*There is another fac
tor that need to count in this study, so need to extend more valuable factors

DISCUSSION

This is the first study to precisely explore the relationship between loneliness and life satisfaction among the caregivers of children with LLI in Kelantan. The study also explored the associated factors related to the sociodemographic profiles of caregivers and their children with LLI with loneliness.

Majority of the caregivers in this study were females predominantly the mothers compared to male caregivers. This could be attributed to the fact that mothers traditionally spend more time caregiving for children with LLI and are often more knowledgeable about their child's condition than other caregivers such as fathers and relatives. Despite both father and mother possess caregiving and parental duties, commitment of caregiving often is under maternal responsibilities (16).

In addition to that, this study also discovered a lower level of loneliness (ULS-8 score: 8 - 13) among participants, especially mothers. This was because mothers were more actively responsible for providing care for children with chronic illnesses (17), and they spent most of their time caring for their children and seeking medical attention (18). In this study, mothers were seen to be emotionally committed to the course of disease trajectory and shoulder a greater responsibility when caring for an ill child. Despite the challenging situations and consequences, female caregivers possessed higher determination to continue their caregiving role (19).

Based on the outcome of this study, non-Malay participants accounted for less than 5% of the total participants. Kelantan is a predominantly Malay state, with strong Islamic background (20). Most of the participants involved were unemployed. Hence, majority of them would function as informal caregivers and may have received minimal monthly allowance, compared to normal population. This was supported by the mean household income being just above the poverty line, RM 2614.27 (SD = RM 2592.98) indicating the overall demographic of caregivers involved (21). Furthermore, this study also has revealed employed caregivers reported to have far lower degrees of loneliness than retired or unemployed caregivers. This was similar to Rubira et al. (22), which found that unemployed caregivers typically felt more alone and lonelier. This could be because these groups of caregivers had fewer daily social encounters due to minimal or limited social activities and while caring for their child.

Traditionally, caregivers experiencing higher levels of loneliness were susceptible to life dissatisfaction. In this study, most of the caregivers of children with LLI in Kelantan had moderate to high levels of loneliness but less than 10 % of them were dissatisfied with their life. A similar study among the caregivers of schizophrenia patients revealed most caregivers did not voice any complaints even though they had a heavy caregiving workload (23). Thus, we speculated that this discrepancy was a result of the homogenous Malay Muslim population using religiosity as the mode of coping (24,25). Since this study was conducted in Kelantan, a state well-known for its strong Islamic teachings and practices in Malaysia, this coping technique practice may have been related to their Islamic beliefs and faith. Therefore, it is important for future research to explore these coping mechanisms as part of quality-of-life study.

Ekwall 2005 found a significant correlation between loneliness and poor quality of life (26). However, this statement was inconsistent with our findings. In this study, we did not find any correlation between loneliness and life satisfaction among the caregivers of children with LLI in Kelantan. This differences perhaps stemmed from the difference in methodological assessment of the instrument and demographic variability used to screen for loneliness and life satisfaction. We suspect caregiver parents were able to deal with stressors when handling and caring for their children with LLI. Even though we have utilized validated instruments in Malay language, some of the items to assess life satisfaction were redundant. For example, when caregivers were asked to express their "ideal", "excellent" and "life satisfaction", which each caregiver might have interpreted differently based on their general or individual understanding of the terminology given. Pavot et al indicated that SWLS items provide a global assessment of life satisfaction rather than focusing on specific life domains. This should allow the participants to weigh on various life aspects according to their personal experiences, values and perspectives (27).

Limitation

There are some limitations in this study. Firstly, this study was a cross-sectional study, and it would not be a representative of the entire Malaysian population. The data represented only the informal caregivers of children with LLI who came for outpatient follow-up at the Paediatric clinic in Hospital USM or those that had been registered under YOKUK Sayangku HOME care, instead of involving other health clinics in other districts or other states. Therefore, future research may consider expanding the target population to other parts of Malaysia such as in the West Coast of Malaysia. Secondly, many participants in this study were female and Muslim which might lead to different psychological expressions, taking into consideration that they might turn to religiosity as a coping mechanism. Furthermore, the culture practice in Malaysia is different from those in European countries. Caregivers are often willing to take time off or respite care from caring for their children. These might contribute to the population bias, where the outcome might be different. Another limitation, there is a possibility of response bias using guided questionnaires within this short period of study and the caregiver's understanding about the questionnaires. This

also might contribute to variable effects on the outcome.

CONCLUSION

We found that the loneliness among the caregivers of children with LLI in Kelantan did not affect their level of life satisfaction. Factors such as employment status, household income and the number of family members were strongly associated with higher level of loneliness among these caregivers. Screening for loneliness, especially for those with risk factors, must be carried out for an early intervention. Coping mechanisms using religious context should be explored in future studies. Larger data collection is required to establish the significance of other factors which might influence loneliness and life satisfaction among the caregivers.

ACKNOWLEDGEMENT

Special thanks to Homecare team (YOKUK) for the collaboration in data collection. Secondly, we also wish to thank all caregivers from this study who have openly share their challenges and tribulations. Thirdly, I would like to thank staff from Paediatric department for the help and cooperation.

REFERENCES

1. Perlman D, Peplau LA. Toward a social psychology of loneliness. Personal relationships. 1981 May; 3:31-56. Available from: https://peplau.psych.ucla.edu/wp-content/uploads/sites/141/2017/07/Perlman-Peplau-81.pdf
2. Makhtar A, Ab Ghani NN, Elias SM, Ludin SM. Social support and associated factors among family caregivers of older people in North-East Peninsular Malaysia. Belitung Nursing Journal. 2023;9(1):69. Available from: https://doi.org/10.33546/bnj.2334
3. Abu Bakar SH, Weatherley R, Omar N, Abdullah F, Mohamad Aun NS. Projecting social support needs of informal caregivers in Malaysia. Health & social care in the community. 2014 Mar; 22(2):144-154. Available from: https://doi.org/10.1111/hsc.12070
4. Taniguchi Y, Miyawaki A, Tsugawa Y, Murayama H, Tamiya N, Tabuchi T. Family caregiving and changes in mental health status in Japan during the COVID-19 pandemic. Archives of gerontology and geriatrics. 2022 Jan 1;98:104531. Available from: https://doi.org/10.1016/j.archger.2021.104531
5. Hadi AA, Abidina MA, Ismail MN, Ahmad I. A study on burden among caregivers of stroke patients. IIUM Medical Journal Malaysia. 2016 Jun 1;15(1). Available from: https://doi.org/10.31436/imjm.v15i1.1260
6. Dhar RL. Living with a developmentally disabled child: attitude of family members in India. The Social Science Journal. 2009 Dec 1;46(4):738-55. Available from: https://doi.org/10.1016/j.soscij.2009.05.009
7. Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. The Journal of Child Psychology and Psychiatry and Allied Disciplines. 1998 Jan;39(1):29-46. Available from: https://doi.org/10.1111/1469-7610.00302
8. Association for Children with Life-threatening or Terminal Conditions and their Families, Baum D. A guide to the development of children's palliative care services. Association for Children with Life-threatening or Terminal Conditions and their Families; 1997. Available from:https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-5.pdf
9. Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: development and pilot study of a 'Directory 'of life-limiting conditions. BMC palliative care. 2013 Dec;12:1-5. Available from: https://doi.org/10.1186/1472-684X-12-43
10. Swami V. Psychometric analysis of the Malay version of the UCLA Loneliness Scale (ULS-8) and a comparison of loneliness among sojourning and non-sojourning Malaysian students. International Journal of Culture and Mental Health. 2009 Jun 1;2(1):38-50. Available from: https://doi.org/10.1080/17542860802560397
11. Swami V, Chamorro-Premuzic T. Psychometric evaluation of the Malay satisfaction with life scale. Social Indicators Research. 2009 May;92:25-33. Available from: https://doi.org/10.1007/s11205-008-9295-7
12. Suldo SM, Riley KN, Shaffer EJ. Academic correlates of children and adolescents' life satisfaction. School Psychology International. 2006 Dec;27(5):567-82. Available from: https://doi.org/10.1177/0143034306073411
13. Schoenmakers B, Buntinx F, De Lepeleire J. Supporting the dementia family caregiver: the effect of home care intervention on general well-being. Aging and Mental Health 2010; 14(1): 44-56. Available from: http://doi.org/10.1080/13607860902845533
14. The Provincial End-of-Life Care Action Plan for British Columbia. Available from: http://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf
15. Bonin-Guillaume S, Arlotto S, Blin A, Gentile S. Family caregiver's loneliness and related health factors: what can be changed? International Journal of Environmental Research and Public Health. 2022 Jun 9;19(12):7050. Available from: https://doi.org/10.3390/ijerph19127050
16. Fisher V, Fraser L, Taylor J. Experiences of fathers of children with a life-limiting condition: a systematic review and qualitative synthesis. BMJ Supportive & Palliative Care. 2023 Mar 1;13(1):15-26. Available from: https://doi.org/10.1136/bmjspcare-2021-003019

17. Adib-Hajbaghery M, Ahmadi B. Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. International journal of community-based nursing and midwifery. 2019 Oct;7(4):258. Available from: https://dx.doi.org/10.30476/ijcbnm.2019.73893.0
18. Keklik D, Bayat M, Başdaş Ö. Care burden and quality of life in mothers of children with type 1 diabetes mellitus. International Journal of Diabetes in Developing Countries. 2020 Sep; 40:431- 435. Available from: https://doi.org/10.1007/s13410-020-00799-3
19. Ramli FZ. Malay Women's Perspectives as Primary Caregiver to Older Adults with Mental Health Problems: A Qualitative Study. International Journal of Social Policy and Society (IJSPS). 2022 Dec 28:9-35. Available from: https://ijsps.ism.gov.my/IJSPS/article/view/251
20. Pawanteh MR, Kuake JB. Orghe Kelantan: A preliminary study. International journal of culture and history. 2016;2(4):184-8. Available from: https://doi.org/10.18178/ijch.2016.2.4.061
21. Household Income Survey Report 2022, Department of Statistics Malaysia (DOSM). Available from: https://open.dosm.gov.my/dashboard/household-income-expenditure
22. Rubira EA, Marcon SR, Belasco AG, Ganva MA, Espinosa MM. Burden and quality of life of caregivers of children and adolescents with chemotherapy treatment for cancer. Acta Paulista de Enfermagem. 2020;25(4):567–73. Available from: https://doi.org/10.1590/S0103-21002012005000020
23. Salleh MR. The burden of care of schizophrenia in Malay families. Acta Psychiatrica Scandinavica. 1994 Mar;89(3):180-5. Available from: https://doi.org/10.1111/j.1600-0447.1994.tb08089.x
24. Mohd Suhaimi M, Nasrudin S, Ezarina Z et al. Cultural Influences in Mental Health Help-seeking among Malaysian Family Caregivers. Pertanika J. Soc. Sci. & Hum., 2014; 22:1-16. Available from: https://www.researchgate.net/publication/284015053
25. Azman A, Jamir Singh PS, Sulaiman J. Caregiver coping with the mentally ill: a qualitative study. Journal of Mental Health. 2016; 26 (2),98-103. Available from: https://doi.org/10.3109/09638237.2015.1124395
26. Ekwall AK, Sivberg B, Hallberg IR. Loneliness as a predictor of quality of life among older caregivers. Journal of advanced nursing. 2005 Jan;49(1):23-32. Available from: https://doi.org/10.1111/j.1365-2648.2004.03260.x
27. Pavot W, Diener E. Review of the satisfaction with life scale. Psychological assessment. 1993 Jun;5(2):164. Available from:https://doi.org/10.1037/1040-3590.5.2.164