Quality of Life of Epilepsy Caregivers: Caregiving Stress and Epilepsy Caregiver Support Services in the Hong Kong Context

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Abstract

Background

In Hong Kong, caregiver burden (CB) in epilepsy constitutes a huge understudied area and related researches are long overdue. This study attempts to identify the stressors, its affect and the copings of the epileptic caregivers.

Methods

This research undertook a comprehensive assessment of caregiving burden and difficulties associated with informal caregiving in Epilepsy with mixed methods of data collection and analysis. Familial caregivers (FC) (N=38) completed questionnaires providing demographic, disease-related, and burden information of the care receiver with epilepsy (N=43). The researcher assessed the CB using the Chinese version of Zarit Caregiver Burden Interview (ZBI). Two caregivers and former staff of the epilepsy-related agency were prompted to identify difficult aspects of epileptic caregiving experience, reflecting on their responses to the life story interview and locating the current service gap of within the policy and formal social service in semi-structured interviews.

Results

The total scores of the ZBI ranged from 41 to 77. Most family caregivers felt moderate to severer of caregiving burden (N=38; M = 58.37; SD = 11.01). Two factors, “Sacrifice and Strain” and “Inadequacy”, were seen as the significant variances that contributing caregiving burden. A high positive correlation between caregiving time spent and caregiver ZBI score was found.

Conclusions

The collection and analysis of quantitative and qualitative data better explore the complexity of caregiver burden in Epilepsy. The result of both data reported caregivers experienced stigmatisation, finances and other stressors. These stressors mostly influence caregivers’ emotional well-being, family

and social life etc., making them often have trouble finding the right coping strategies. The implication of caring for patient with Epilepsy (PWE) allows social care providers and policy makers for better supporting the caregiver in the community.

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List of Abbreviations

Abbreviations	Full form
CB	Caregiver Burden
CS	Caregiving Stress
CSSA	Comprehensive Social Security Assistance
CR	Care Receiver
HK	Hong Kong
NGO	Non-governmental Organisation
PWE	Person with Epilepsy
SSA	Scheme and Social Security Allowance
QOL	Quality of Life
ZBI	Zarit Burden Inventory

List of Tables and Figures

Table 1

Description of ZBI Factors

	N	Minimum	Maximum	Mean	Std. Deviation
Sacrifice and strain (ZBI-1)	38	16	35	25.97	5.943
Inadequacy (ZBI-2)	38	4	8	6.50	.952
Embarrassment/Anger (ZBI-3)	38	2	9	6.32	1.710
Dependency (ZBI-4)	38	3	11	7.58	2.309
Loss of Control (ZBI-5)	38	6	14	8.92	1.792
Valid N (listwise)	38				

Table 2

Description of Total ZBI Scores

	N	Minimum	Maximum	Mean	Std. Deviation
Total ZBI Scores	38	41.0	77.0	58.368	11.0145
Valid N (listwise)	38				

Table 3

Correlation between Caregiving Time Spent Per Week and Total ZBI Scores

		Caregiving Time Spent Per Week (Hours)	Total ZBI Scores
Caregiving Time Spent Per Week (Hours)	Pearson Correlation	1	.912**
	Sig. (2-tailed)		.000
	N	38	38
Total ZBI Scores	Pearson Correlation	.912**	1
	Sig. (2-tailed)	.000	
	N	38	38

Note. Correlation is significant at the 0.01 level (2-tailed).

Introduction

The researcher spent five months working as student social worker in a the only agencies that is bilingual, non-medical and non-government organisation (NGO) called Enlighten-Action for Epilepsy, expresses concern and advocates the rights of epilepsies in Hong Kong (The Hong Kong Council of Social Service, 2019; Enlighten – Action for Epilepsy, 2019). The work related with the caregivers could be very emotionally, isolating from the community and resources are merely sufficient for them to access. Caregivers and social workers as a helping alliance, at the same time, carried numerous responsibilities that are eventually leading to stress and exhaustion.

Research and studies on epileptic caregiver stress and support services in Hong Kong (HK) have not been sufficiently investigated the epidemiology of epilepsy, even though epilepsy is demonstrated as the most common chronic severe neurological condition in covering 94% of the world population (World Health Organisation, 2017). The latest research on the psychosocial well-being of epilepsy caregivers in Hong Kong was developed in 2002 (Lee et al., 2002). Now, over 17 years later, the stresses of epilepsy caregivers may have loaded significantly due to social change. As the research gap constitutes an essential yet hugely unstudied area and tremendous uncertainty that have not yet resolved and often neglected by the public – up-to-date research is needed.

Since there are no official community support services made mainly for the abovementioned group, the researcher believed that the social care support service of this vulnerable group in Hong Kong could be improved, and they needed to be supported by the general public - especially for those with a lack of self-advocacy skills and have complex support and health needs. Social workers and other professionals should be started to change the service delivery model in the current social welfare system which is epilepsy-related and adequately support the targeted clients not just in formal welfare aspect, but also make references from some of the other countries, which could then positively influence the quality of support as well.

This study will investigate the stressors that the informal caregivers often encounter, what experiences they have and how such stressors and experiences affect their quality of life (QOL) and their copings as individuals on all levels, including physical, psychological and social level. As such, it helps to understand their needs, propose recommended chapter on how to sustainably and efficiently strengthen social care and health care of epilepsies and their caregivers. The general aim is to inform the authority the problems facing by epileptic patients and epilepsy caregivers, enhancing their QOL by suggesting social support services options in Hong Kong.

Conceptual Framework

Ecological systems theory is adapted as a lens, guiding the interpretation of collected data and evaluation of the study. The model is divided into four levels; they are microsystem, mesosystem, exosystem and macrosystem (Onwuegbuzie, Collins, & Frels. 2013). This quantitative and qualitative study is in the levels of microsystem, mesosystem, and macrosystem, particularly the mesosystem. The mesosystem refers to "the interrelations among two or more settings in which the person actively participates among family, work and social life" (Onwuegbuzie, Collins, & Frels. 2013, p.4).

By applying the conceptual framework of ecological systems, specifically the mesosystem, this study seeks to identify the stressors that affect the quality of life of epilepsy caregivers in HK. It is crucial for social workers, policymakers, and other professionals to understand their role in providing support to family caregivers, establish the cornerstone of networking by suggesting associated support services for this group in HK.

Literature Review

A literature review will be performed below, discussing the concepts of Epilepsy, familial caregiver, quality of life (QOL), caregiving burden (CB), and caregiver coping, as well as stigmatisation with theoretical framework applied and methodologies of previous studies. The limitations of the previous studies and existing research gap will be also addressed.

Epilepsy

Epilepsy identifies as the condition with neuronal excitability, characterised preponderantly by unpredictable and recurrent seizures in cerebral origin due to disturbances in its electrical functions (Fisher, Boas, Blume, Elger, Genton, Lee, & Engel, 2005; WHO, 2017). It leads to an unprovoked, "involuntary change in body movement, sensation, awareness, or behaviour" (Hodge, Lieberman & Murata, 2017). The latest prevalence rate for epilepsy in Hong Kong was reported in Hui and Kwan's study (2004), they estimated that approximately 4.5/1000 individuals have active epilepsy. The scientific validity of epidemiological studies on epilepsy in Hong Kong is exceptionally overdue.

Familial Caregiver

Kim, Chang, Rose & Kim (2011) defined caregiving as "persons who assisted individual with at least one activity of daily living", assisting in financial management, household, daily living and/or medical tasks. Providing care for family members dates to the earliest years of humanity (Link, 2015). Familial caregiver is informal caregiver, they can be a spouse, adult child, in-law or close relative (Noelker & Browdie, 2012).

Quality of Life

QOL (Diener, 1984) refers to the subjective well-being of individuals and constructed by societies, emotionally and cognitively evaluating of their lives. The significance of observing life satisfaction was emphasised by Barcaccia (2013), concerning physical health, family, financial status, environment etc. Karakis et al. (2014) adapted the instruments of QOLIE-31 and Zarit caregiver

burden inventory, evaluating how epilepsy influence caregiver's QOL in their cross-sectional study. Collected data reflected that QOL scores of epileptic caregivers are averaged 54, which associated with worse physical health, lower social function level, higher depression scores etc. Situations like patient's unemployment, longer disease duration, shorter periods of seizure freedom would be the stressors that contribute to caregiving burden. Another deficient study finding proposed by Karakis et al. also found on the caregiver burden in epilepsy and the associated effect on their QOL of caregivers.

Caregiving Burden

Collins et al. (1994) defined caregiver burden as the negative objective and subjective outcomes such as "experiencing psychological distress, physical health problems, economic and social problems, breakdown of family relationships and feeling of despair which are brought about by the caregiving burden undertaken by the caregiver". In this study, Zarit caregiver burden inventory (Zarit, Reever, & Bach-Peterson, 1980) would be the instrument of evaluating the caregivers' caregiver burden. The 22-item self-administered questionnaire comprises 5 domains: (1) sacrifice and strain (8 items), (2) inadequacy (2 items), (3) embarrassment/anger (3 items), (4) dependency (3 items), and (5) loss of control (4 items). It would be adapted as the instrument of this study.

Attachment. Caregiving burden implied the concept of "caregiving burden", implied the concept of "attachment" which suggested in the attachment theory (Bowlby, 1969). The interactions between primary caregivers and patients in the early stage of life, individuals would develop mutual, continuing cognitive schemas (attachment orientations) that sustain into adulthood and guide day-to-day behaviours and expectations in relationships. The sense of connecting with another person is related to the concept of dependency (Sigelman & Rider, 2014).

Stress Level. The study of Yigitalp (2017) suggested stress level is a significant predictor for caregiver burden; it is proven that a positive correlation between caregiver burden and stress level of the caregiver. This further explained high-level stress would increase the caregiving burden as evident in Yigitalp 's descriptive study (2017).

Psychological Health Effect. Resonating diathesis-stress model, it is identified that "stress may activate a diathesis or vulnerability, transforming the potential of predisposition into the actuality of psychopathology" (Monroe & Simons, 1991). As mentioned in Bevans's study (2012), it is common that caregiving stress (CS) causes psychological problems. Signs and symptoms of CS, such as anxiety, depression, worry and loneliness, are deleterious to one's health. Similar to the above findings, caregivers have lower levels of self-care, for example, taking enough time for themselves and deterioration of family relations, because of their caring responsibilities (Ozyesil, Oluk & Cakmak, 2014). Nevertheless, the physical effect on health is not mentioned in the literature.

Financial Pressures. As demonstrated in Allers et al.'s cross-sectional study (2015), Epilepsy added a substantial economic burden for the whole health systems and epileptic individuals and their families. This could be related to the financial costs incurred in the daily medical care, the impact of the disease on the employment status of caregivers due to difficulty finding and maintaining jobs that accommodate their family member's care needs.

Stigmatization

In Karakis et al. 's study (2014), a positive correlation between unpredictability and high grade of stigmatisation is proven. It is associated with the descriptions of seizure symptoms of epilepsy. In China, these descriptions are often influenced by the traditional and pejorative beliefs about epilepsy that still widely exist. Guo et al. (2012) suggested the stigma of people with epilepsy is demonstrated at the internalised, interpersonal and institutional level in the Chinese socio-cultural context. Another finding is that negative self-evaluation of epilepsy and their caregivers, "accompanied by a negative emotional experience stimulated by the responses of others".

Caregiver Coping

Epileptic caregivers have their unique ways of coping with facing challenges of caring for PWE. Coping may be defined as a "process of adaptation to stressful situations", which includes the

"allocation of cognitive and behavioural resources in response to specific internal and/or external demands that are deemed to exceed the subject's normal requests" (Folkman & Lazarus, 1980). The first coping is task-focused coping, people with this coping seek to actively work on a task that will solve the problem or make the problem better, such as having a sense of control over the challenges by organising, searching information and planning. Higgins & Endler (1995) noted that if the frequency of task-focused coping increases, the distress would be decreased.

Second, caregivers with emotion-focused coping strive to regulate distressing emotions. Many of them would have emotional expression, fantasising, and keep reflecting on either positive or negative thoughts (Bauman, Haaga & Dutton, 2008).

Third, Higgins & Endler (1995) pointed out that avoidance-focused coping includes escaping from adverse situation and includes social diversion. Williams, Morrison, & Robinson (2013) added on that feelings of helplessness also presented as avoidant coping behaviours, particularly when caregivers are feeling a poor QOL for themselves or their CR and loss of control. Examples for people have this coping behaviour, they would stop bringing their CR to social events or public areas so as to maintain their CR's dignity, protect both themselves and the CR from "humiliation" or "embarrassment" (Williams, Morrison, & Robinson, 2013).

Several studies (Higgins & Endler, 1995; Bauman, Haaga & Dutton, 2008; Thompson, 2009) have suggested that emotion-focused and avoidance-focused coping strategies may be dysfunctional, as people with these copings distract from understanding or dealing with requests due to both increased physiologic and psychologic distress.

Considering what the literature says about CB, it is worth further study to identify other stressors, discover the power of its affects, an also how caregivers and the former staff of Enlighten view their situations and providing additional social resources, support to caregivers. Research questions of the study are 1. "What are the caregiving stressors of people with epilepsy?", 2. "How

stressors affect that quality of life of epileptic caregivers?", 3. "What and why are the coping strategies are key to epileptic caregivers?".

Methodology

Study Design

A descriptive, correlational research design with the mixed method was employed to generate a broader variety of data, particularly a quantitative questionnaire conducted with standardised measures through simple random sampling. Followed up by qualitative interviews comprising two individuals who had participated in the survey through snowball sampling, depended on a semi-structured interview technique developed with open-ended questions in assessing aspects of caregiver burden. An interview for the former staff who worked at the agency, in particular, serves the PWE and their caregivers, she interpreted the current situation, service gap and what she may advocate and suggest.

Sampling Method

After the pilot test questions and script were prepared, non-probability sampling was adopted to reach the target group. The researcher sought former staff of Enlighten – Action for Epilepsy for referral, epileptic caregivers were invited to fill the questionnaire; and both caregivers and staffs were invited to participate in the interviews by snowball sampling.

Inclusion and Exclusion Criteria

Caregiver participants were recruited in Hong Kong. The inclusion criteria for epileptic caregivers are as follows: (a) age ≥ 18 years; (b) ability to communicate in Chinese; and (c) providing written informed consent. Exclusion criteria contain (a) diagnosis of seizure other than Epilepsy; (b) self-care patient. All participants were informed about the study aims and give their consent to participate in the face-to-face interview.

Recruitment

Since the invitations were sent to Enlighten – Actions for Epilepsy through e-mail and phone calls, but there was no reply. FC were therefore recruited into this study through referrals by former staffs and personal contact as a ground-work approach, then adapt snowball sampling to potential respondents and to seek their consent for the interview. A list of general questions will be attached to the invitation (Appendix B), while the researcher will ensure the confidentiality and the freedom of right in stopping information provided at any stage of the interview.

Data Collection

Depth interviews defined as creating "categories from the data and then to analyse relationships between categories" while attending to how the "lived experience" of research participants can be understood (Charmaz, 1990, p. 1162). Except literature search, both questionnaire (Appendix A) and semi-structured depth interviews (Appendix B, C), quantitative data were collected on a range of demographic and socio-economic variables. Standardised validated measure in accessing the caregiving burden was evaluated by completing the ZBI instrument. Each question is scored on a 5-point Likert scale ranging from – "never" to "always present".

The interviews were conducted by the researcher and lasted between forty-five minutes to ninety minutes in Chinese. Participant observation in interviews was adopted. All interview set in private meeting areas specified by the participant's preference participants preferred - in a restaurant or office where they lived around. Both caregivers and former staff of Enlighten-Action for Epilepsy, a series of three introductory questions were included, fourteen (Appendix B) and eight focused questions (Appendix C) that used a semi-structured format were asked respectively. The researcher kept transcripts (Appendix D, E, F) as documentation of key insights, observations of verbal and non-verbal communication and analysed using grounded theory to understand the participants' responses further. The researcher then coded each answer or phrase to discover overall themes, sub-themes and categories.

Analysis

A mixed methods analysis was undertaken to provide additional coverage; each analysis method has a separate purpose matching the strength of that method. The researcher analysis of quantitative and qualitative data for caregivers (n = 38) and care receiver (n = 43). In this study, the results are presented separately, with integrated interpretation in the discussion narrative.

Descriptive statistical analyses were performed using SPSS v23 to describe characteristics of the caregiver and care receiver cohort, and measures of subjective caregiver burden.

Ethical Issue and Confidentiality

The researcher is responsible for the content and writing of the paper; she will ensure the confidentiality, privacy - written informed consent is obtained from the participants. Participants have the right to withdrawal at any time during the interview process. Ethics approval will be sought from Gratia Christian College.

Research Outcome

Stressors, its affect and coping strategy of caregivers will be analysed, whilst implications of caregiver support service would also be discussed, based on the analysis and references of the data collected in the data collecting process.

Results

A total of 60 questionnaires were distributed, and the response rate was sufficient where 38 questionnaires (63%) were collected back for further analysis.

Descriptive Statistical Analysis

Characteristics of Familial Caregivers. Thirty-eight participants were recruited in the study. The ages of FC ranged from 30 to 69 years old, with a mean age of 52 years (SD = 9.88). The study included 13 men (34%), 25 women (66%). The relationships of family caregivers to care receivers included 17 daughters (39.5%), 16 sons (37.2%), one husband (2.3%). The mean length of being a caregiver was 15 years (SD = 9.98), including 38 participants for less than 5 years (23.6%), 5 years to 15 years (34.2%) and more than 15 years (42.1%). This information was self-reported and included the following: 1-50 hours per week, 42.1% (n=16); 51-100 hours per week, 21.0% (n = 8); 101-150 hours per week, 10.5% (n = 4); and 168 hours per week, 26.3% (n=10); The mean caregiving time spent of 86.2 hours (SD = 60.19). The number of time caregivers stated they spent doing these activities varied according to the need of the PWE. Thirty-two caregivers were the only-caregivers, while only 6 of them were not. The caregivers sampled also reported multiple chronic illnesses that they exhibited (e.g., diabetes, high blood pressure, diabetes, stroke sequelae, depression, Alzheimer's disease, and cancer). In response to question of perceived health condition from “never” (1) to “always” (5), 3 (7.9%) respondents reported “always”, 6 (15.8%) “quite frequently”, 9 (23.7%) “sometimes”, 17 (44.7%) “rarely”, and 3 (7.9%) “never” (M = 2.71; SD = 1.09).

Characteristics of Care Receivers. The gender of care receivers broke down to 26 men (59.3%) and 17 women (44.7%). The age of care receivers ranged from 6 to 71 years, with a mean age of 21.63 years (SD = 10.98). Eighteen PWE received care from their FC since they were born, while other cases occurred with unknown reason or by accident.

Descriptions of ZBI Scale. The summed caregiving burden scores of caregivers assisting PWE with ZBI corresponded to never (0), rarely (1), sometimes (2), quite frequently (3) and always (4). The higher scores indicate a higher family caregiver burden. For Factor I, Sacrifice and Strain subscale, contained eight questions: # 2, 3, 7, 10, 11, 12, 13 and 15. The total scores of Sacrifice and Strain subscale ranged from 19 to 34. Family caregivers felt that they experienced a high level of sacrifice and strain (M = 25.97; SD = 5.94) (Table 1).

About Factor II, the Inadequacy subscale included two reversed questions, # 20 and 21. The total scores of Inadequacy subscale of respondents ranged from 5 to 8. FCs felt that they had a significantly high level of inadequacy (M = 6.60; SD = .952) (Table 1).

Regarding Factor III, three questions were included within the Embarrassment/Anger subscale, # 4, 5 and 6. The total scores of Embarrassment/Anger subscale of respondents ranged from 2 to 9. FCs perceived a medium level of embarrassment or anger (M = 6.32; SD = 1.71) (Table 1).

For Factor VI, Dependency subscale included three questions, # 1, 8 and 14. The total scores of the Dependency subscale of respondents ranged from 3 to 11. Caregivers felt that care receivers had a moderate level of dependency (M = 7.58; SD = 2.30) (Table 1).

For Factor V, the Loss of Control subscale included four questions, # 16, 17, 18 and 19. The total scores of the Loss of Control subscale of respondents ranged from 6 to 14. Caregivers felt a moderate level of loss of control (M = 8.92; SD = 1.79) (Table 1).

Overall, the total scores of the ZBI ranged from 41 to 77. Most family caregivers felt a moderate to severer of caregiving burden (N=38; M = 58.37; SD = 11.01) (Table 2).

Correlations between ZBI and Caregiving Time Spent. Results of the Pearson correlation indicated that there was a significant positive association between and ZBI total scores of respondents, ($r(37) = .91$, $p < .001$) (Table 3). Family caregivers who caregiving time spent per week and their total

scores of ZBI was increasing experienced a greater caregiving burden. Family caregivers who had lesser caregiving time spent experienced a lower caregiving burden (Table 3).

Thematic Analysis of Qualitative Data

Physical Condition. The internal and external physical condition could be one of the difficulties, referring long-term management on rapidly evolving the declining or disabling condition related to PWE' functional status, behaviour, and communication barriers, and the extra caregiving tasks required.

Daily Routine. Declining physical function, seizure frequency, impaired cognition/behaviour of PWE and communication contribute to difficult experiences for the caregiver. The extra tasks included dealing with the tantrum of the PWE, assistance with activities of daily living, washing, medical check-ups and personal care as illustrated by the quote: "My daughter has serious constipation. When she is changing on her dosage, she has difficulties on alertness and concentration, I am struggling with protecting her safety; my daughter has emotional and behaviour problems, she was self-harmed" (mother, 64 years old). (father, 30 years old). The increased physical demands on the caregiver, such as physical effort on daily routine and ensure for patients' safety.

Health Condition of Caregivers. Both father (30 years old) and mother (64 years old) reported worse physical health, pain and poor sleeping quality. The father addressed, "now thinking back, I lacked sleep. My body muscles are so painful for no reason; I also have joint strain".

Psychosocial and Emotional Wellbeing. Caregiving stressors influence on the aspects of the psychosocial and emotional well-being of the caregiver. Two caregiver informants indicated anger, fear, worry, hopelessness, helplessness, stress, frustration, and uncertainty associated with providing care to their children. The researcher observed during the interview discovered that caregivers have frustration at the inability and inadequacy in restoring QOL of the PWE. In particular, when their child physical and cognitive levels are declining, having one-way communication with PWE, as illustrated

by the quote: …"sometimes my daughter ignores me, I do not know whether she is having absence (a kind of seizure that PWE would temporarily loss of consciousness)" (mother, 64 years old).

Caregivers always flooded with negative emotions and *memories.* "I saw her [my daughter] was struggling with handwriting, I thought she was lazy, so I mad at her" (mother, 64 years old). The emotional aspects of providing care were experienced as sometimes more difficult than the physical ones. The mother added on saying that she felt impatient with the emotional needs of her daughter as she "pulls off her hair to express her hunger, having a bad temper when she does not want to eat vegetables and so on" (mother, 64 years old).

Sense of uncertainty and fear about the future. "It's like forever…I am growing old" (father, 30 years old), of not knowing what will happen or how to deal with the future: "I always cry for my inability to take care of her [daughter], feeling worried…everything is loss of my control. Alertness and concentration, I am afraid that what she will do without me" (mother, 64 years old). For some there can be uncertainty over their capabilities as a caregiver, no matter is at the past, present or in future, they are unsure if the care provided is adequate and sufficient.

Role overload. The role overload was a presenting problem of lack of freedom; caregivers want to bear all the responsibilities, finishing and preparing the acquired tasks the PWE used to complete. Seeking for help and learning to accept help offered by the others would minimise overload. Like mother (64 years old) said that she would ask her neighbour to take care of her daughter for an hour or two. Sub-theme concerning common challenges caregivers bring up in conversation, and both interviewees described themselves as "trapped" in their caregiving role. Even when the caregiver is sick and need to enter hospital, "I feel helpless. I have no choice when I also have emotions, so I put her into respite care, even though I feel really regret after that (mother, 64 years old). This caregiver also feel that the emotions are insurmountable, they may experience depression and have suicidal thoughts.

Secondary Trauma. Exposing under the psychological and emotional impacts, suffering and deterioration of the PWE is another major subtheme in this qualitative analysis… "just seeing her distress about my anger, how can I beat her?" (mother, 64 years old). There is emotional distress at witnessing the declining abilities to the PWE. The patient's condition deteriorates, and the caregiver loses the control, "I can only self-comforting, I can do nothing" (mother, 64 years old).

Intra-relationship and Inter-relationship. Providing care and the role of caregiver impacts on relationships, sometimes alter family dynamics, and how caregivers relate to other people and themselves.

Lack of Support. Referring to his family, one father commented that now "The reason for my divorce with my ex-wife is about two children; even my family members said they do not mind visiting me, we seldom contact each other, as I am not outstanding enough to give birth to the sons that make them [family members] pound" (father, 30 years). Caregiving changes existing relationships and presents new expectations and role reversals "I became the private tutor of my sons" (father, 30 years). It is hard for some to reconcile the caregiver, family members, and care receiver relationship with their prior relationship, especially when the caregiver has to bear more responsibilities in caregiving, "My partner passed away, I start thinking another way, wanted to die so much; I was not supported and I do not know any place or anyone can offer help" (mother, 64 years).

Social Stigma. People often consider epilepsy to be a form of insanity; some would suggest social avoidance and exclusion: "My daughter screamed and hit people from the beginning; some people will say to me - what's wrong with you? Why would you bring her [my daughter] out?" (mother, 64 years).

Only-caregiver. Identity is related to the responsibility of oneself. Only-caregiver sometimes can be accompanied by a change in how the caregiver sees him/herself: "I am his father, yet I am now

becoming their caregiver, tutor, breakfast maker etc." (father, 30 years) — coming to terms with 'becoming their caregiver' and its impact on self-perception.

Limitation and Constraint. The relentless and usually time-delimited course of PWE is reflected in the theme of limitation and constrain.

Lack of Freedom. A lack of freedom means "if I do not need to take care them [my sons], I would be able to work, trapped myself and have more chance for socialising" (father, 30 years).

Role Constraint. The relentless aspect of the caregiving role was summarised as " I am the only-caregiver; the work just never stops." (father, 30 years old). Teir lives have changed, "I hadn't gone out with my friends and family a long time ago. Even I wanted to relax; I found an excuse to reject my friends' invitation, except other friends, do not mind I bring my sons with us" (father, 30 years old).

Time Constraint. Providing care and being a caregiver can often be restrictive in their time and place, as caregivers spend more time providing care, activities and time. Increased demands on time, make it a limited and restricted commodity, time is taken from the caregiver and given to the patient "when my sons went to the special school, the breakfast time is the freest time of the whole day" (father, 30 years).

Caregiving Responsibilities. "Doing all the everything, making sure she is okay…" (mother, 64 years). Caregiving responsibilities, especially for parents who provide care, often compete with their work and/or other family commitments.

Discussion

In this study, CB includes physical, psychological, emotional, social and practical challenges which can be faced when providing care for another person. FCs provide a considerable amount of care for PWE, sacrifice and strain and inadequacy are profoundly influence to caregivers' CB. Such results are consistent with findings already reported in the literature (Collins et al., 1994).

Epilepsy generates a number of issues regarding caring for PWE, especially when the persons have chronic disabling conditions. FCs encounter both common and unique challenges and have different caregiving experiences that influence their ability and sense of competence to provide care to PWE. Many factors render the multidimensional elements, making caregiver burden more unique and complex. Epilepsy is characterised by sudden onset and accident, predicted inevitable physical decline, potential cognitive impairment, and sudden death. It is a relentlessly progressive condition with no cure, and currently, no known best treatment as each case is unique, most of the patients can only rely on medicine to control the frequency of seizure.

This caregiver cohort is predominantly parents of the PWE. In the questionnaire, some indicated that they found no much difficulties about caregiving, but when answered the question of "overall how burdened to you feel...?" (Z22) a majority indicated "always" or "quite frequently" burdened. Besides, a mean ZBI burden score (58.37) identified caregivers in need of further assessment and intervention, it placed a majority of informants in a moderate and high burden group. The scores distribution of ZBI-22 items and its mean item scores present fear of what the future holds, do not have enough money, the dependency of care receiver, competing responsibilities and time restriction as major contributors to CB. The analysis of qualitative data in this study offered a more comprehensive perspective and deepen the on identified contributors from the quantitative data and revealed other new aspects.

During the interviews, the self-reported difficulties that disclosed by caregivers could be categorised into four main themes with associated serval sub-themes. The caregiving role and daily tasks related to management of the health and living condition; psychosocial and emotional wellbeing impact as depression and anxiety were manifested in worry, shame, fear and frustration, helplessness and hopelessness. Also, the emotional impact of witnessing PWE suffering accompanied by anticipatory worry at present and future losses. Epileptic caregivers are providing care to their loved one, at the same time, experiencing PWE's illness; they are vulnerably exposed but to suffering and their own distress as an outcome uncontrollably.

This study yields a worth noting correlation, whereas the bivariate analyses revealed a significant positive correlation between the caregiving time spent and ZBI score ($r(37) = .91$, $p < .001$). Meaning that limited time, lack of family and social life and also increasing responsibilities were view as anticipated difficulties associated with providing care. The caregiving role has been dominated on the existing relationship, and there is a powerful impact on inter-relationship, role and identity. Time is also an essential component for dealing with difficulties and emerges as a limited luxury, as time is given to taking care of their family members with Epilepsy, and eventually, self-care time is lost to the caregiver.

These findings are consistent with previous researches on caregiver burden in epilepsy (Nuhu et al, 2010; Karakis et al., 2014) in terms of lessened QOL for caregivers, intensified psychological distress, fear an unknown future, feelings of patient's dependence on the caregiver, taking most of the responsibility of caring, time demands and restriction on the social life of the caregiver. Plus, Monin, & Schulz (2009) mentioned that exposing to the suffering of a loved one and dilemma could be directly affected FCs' emotional experiences, subsequent psychological and also physical health.

Caregiving research has been focused on the role of coping in the adaptation to caregiving (Pakenham, Chiu, Bursnall & Cannon, 2007). Coping varies in different persons; it is an individual

response to stress as a whole and will, therefore, influence mental health during the adverse life events. Task-focussed coping is one of the methods; these group of people would adjust to the caregiving role and responsibilities was associated with more positive adjustment and outcomes. For emotion-focussed coping, it was found in associating negatively with the caregiver adjustment and also linked to increased psychological and emotional distress, especially when caregivers feel that these tasks are their personal responsibility because no one else can do it. Traditional Chinese culture may impact caregiver experiences in several domains, including coping style and utilization of support services. They merely take an initiative role in seeking help and be avoidant. Some may tend to normalise the struggles of caregiving with other caregivers as a way for them to feel less isolated and that the challenges are more universal, making them less alone (Williams, Morrison, & Robinson, 2014).

Implication of Policy, Practice, and Research

Given HK society's interest in cultivating the findings of this study have numerous implications for policy makers and practitioners who are engaging directly and/or indirectly with caregiver of epileptic people. The study findings provided strong support to current literature in regard to caregivers of PWE needing both informal and formal supports. In light of such findings, several implications of policy, practice, and research which are potentially practical will be addressed below.

Policy. In HK, since there is lack of formal support service is available and current policy frameworks have not adapted to meet the needs of a growing number of FC, their access to financial support, flexible employment and social supports that facilitating and enhancing the care of the informal caregivers are immensely limited. Several of the HK social welfare policy the author identified—exceptionally comprehensive caregiver tax benefits and Social Security benefits—Comprehensive Social Security Assistance (CSSA) Scheme and Social Security Allowance (SSA) Scheme (Social Welfare Department, 2019)—do not yet exist in any comprehensive sense.

Therefore, the author suggests the existing policies could serve as scaffolding for a more comprehensive program to respond to caregiver needs with reference the New Policy Strategy from the U.S. proposed by James, Hughes & Rocco (2016). Aiming to relieve the stress of the carers and improve the life quality of the patients with chronic diseases, it could include some combination of the following:

***Tax Credits*.** Expansion of existing Disabled Dependant Allowance tax benefits;

***Social Security*.** Expansion of Higher Disability Allowance (HDA) by relaxing the eligibility criteria of Higher Disability Allowance. For example, allow PWE receiving HDA and receiving care in residential institutions subsidised by the government spontaneously. (including subsidised places in subvented/contract homes and residential care homes under various bought place schemes) or all public hospitals and institutions under the Hospital Authority, or boarding in special schools under the

Education Bureau"; extension of "Caregiving Allowance" into the category of SSA Scheme by fulfilling the regarding eligibility criteria;

***Family and Medical Leave*.** Expansion of incentive grants for paid caregiver leave programs;

***Employment Opportunity and Training*.** Expansion of "Training and Employment Programs", providing initial and ongoing training opportunities during your employment, and;

***Community-Based Care Services*.** Increased and improved appropriations to support the accommodation for the disabled, day training services and respite care.

Practice. Professionals and direct service workers should prepare FCs for their role, and to consider FCs as members of the health-care workforce by relieving their CS and improving protective factor.

***Self-help and Mutual-help Groups as Caregiver Support Services*.** Enhancing protective factors have many ways; it could be a supportive peer network and individual social and emotional competence. Self-help and mutual-aid groups are the informal platform for epileptic caregivers to fulfil the above protective factors. Its establishment would promote the sense of mutual support and install hope among people with epilepsy and their family members by ventilating their feelings and thoughts, enhance the understanding and reduce the stigmatisation of the public about epilepsy, or even advocate for the welfare and rights of PWE and their family members. According to the systems theory (Hanson, 1983), establishing mutual/self-help groups would help to build the cornerstones of networking in which strengthened a part of the system then improve the whole. During the process of identifying and resolving problems, it is facilitating coping networks which conceived as a set of relationships among people with the common aim. Social workers and professionals are the stimuli that facilitate change. While change emerges from a mutual aid, both among people in similar circumstances and their family members, friends and neighbours, and between the network, and social workers, as well as other professionals. Through transforming a positive parent-child attachment relationship, coping strategies

and their sense of competence, it would facilitate not just personal growth, but also community development. The social worker's role is to help the networks to develop reflexivity and improve its ability to enhance welfare. Meanwhile, the networks help the social worker to understand better how he or she can support it (Folgheraiter & Raineri, 2012). Help is constructed through the relationship between practitioners and coping social networks, and that the contribution of those directly concerned is essential to establish the cornerstones of networking.

***Volunteering Program*.** When caregivers are overcoming feelings of hopelessness, they may propose agents of change and spread the hope to others. Through technical, experience sharing, they work as the result of the change in role from “helpee” to helper, facilitating the benefits experienced by member engaged in a helping role as proposed by Reissman (1965). He also suggested that people could improve self-image, committed to self-persuasion through persuading others, going through significant development of abilities after having been given guidance in a system and learning through teaching others when mobilising different systems. Besides, they may also gain access to a socially-valued role as volunteers and the resultant sense of social status and importance and enjoying opportunities to affirm one's wellness following position in a system as a role model, as well as shifting one's focus from self-concerns and problems to assisting others. After having the time of role differentiation and distracting oneself from ongoing difficulties, such copings are a way of altruism, empowering caregivers and their families to be more self-determinate in social participation and affirming their efforts.

Research. Future research should pay more attention on the following points:

Sample Size. The sample size of this study was relatively small; therefore, more population of epileptic caregivers should be recruited in future research.

Directions. There were participants who discussed the accommodation of PWE and the participation of agency operation, which were not indicated hugely in the research. Future research

could focus on the role social workers play in assisting potential caregivers with level of social participation and impact of creasing caregiving.

Limitations

The present study bears two limitations of the findings and implications which need to be considered for future research.

First, self-reporting study nature bears a risk of the inherent bias and social desirability bias; some answers may be exaggerated or too embarrassed to reveal private details. However, self-report scales are widely used, cost-effective methods for caregiving burden.

Second, although the author attempted to search the sample frame, low net accessibility is an encountered difficulty. Participants were recruited by referrals and relying on voluntary participation, so study results can be used only among a population of caregivers who are willing to share their experiences. The modest sample size of caregiver participants may have underpowered this study, resulting in a limitation of generalizability.

Third, this study did not evaluate the caregiver's QOL for providing evidence of construct validity in the present study, since the instrument QOLIE-31 is not available.

Conclusion

Since professionals and advocates together intertwined in the lives process of caregivers of PWE, social workers and policymakers play a significant role in understanding support systems, recognising caregiving burden, engaging families, opening lines of communication and net up the support. Providing a balanced support system for caregivers and families who strive to homecare their family member with epilepsy would be a professional target goal.

To conclude, study findings present high caregiving burden of familial caregivers, and it profoundly affects their quality of life. The results also provide insights on the importance of comprehensive assessment of stressors. It shows that caregiving burden is high when there are too much sacrifice and strain, feeling of inadequacy of caregivers, the dependency of PWE, and loss of control on one's life. Support and both formal and informal social support play a vital part in assisting with stress and burden reduction. Further research is needed in acknowledging and support this vulnerable group. The research purpose was to further add to the out-dated research to reflect that social workers, policymakers and other professionals should identify caregiving stress and providing access to additional systems of support to epileptic caregivers. The research on epileptic caregiving burden needs to continue to explore an integral part that social workers play within the current social service and social welfare policy.

Appendix A

宏恩基督教學院
腦癱症照顧者生活素質研究
問卷調查

本研究由宏恩基督教學院進行，旨在了解本地腦癱症照顧者的壓力與生活素質，以及探討發展相關支援服務的可行性。

此問卷只限本學系研究人員作統計分析之用，所有資料將以匿名形式保存和堅守保密原則。所進行的研究對訪談者不會有任何負面的影響，受訪者亦有拒絕填寫問卷的權利。如有任何疑問，請聯絡協助本研究的同工（如機構職員）或宏恩基督教學院社會工作學系陳凱茵小姐（電話：65946627，電郵：s1503033@gratia.edu.hk）。

一）：研究目的：

本問卷目的是收集腦癇症病人照顧者的狀況，進行統計分析，盼藉以改善照顧者服務，令腦癇症患者、照顧者和家人有所得益。本同意書包括以下內容：

二）填答問卷程序：

你將會填寫一份有關你照顧腦癇症患和日常生活情況的問卷，需時組 15 分鐘。**請留意你所填寫的答案並沒有對錯之分，故請以你的真實經驗填寫，無須與別人討論問卷問題。**以你在填寫期間對問卷有任何不清楚的地方，可隨時向訪問員澄清。

三）參與風險：

參與這項研究是沒有已知的風險。

四）保密範圍：

此問卷只限本研究人員作統計分析之用，所有資料絕對保密，並於研究完成後三個月內銷毀。

五）退出自由：

參與是次研究純屬自願性質。當中如有問題令你覺得回應會感到不安，你有權拒絕回答該問題和在任何時候退出研究。

如有任何疑問，請聯絡協助本研究的同工（如機構職員）或宏恩基督教學院社會工作學系陳凱茵小姐（電話：65946627，電郵：s1503033@gratia.edu.hk）。

由於參與研究屬自願性質，如閣下願意參與，懇請簽署以下同意書。

本人_____已閱讀和清楚了解明白同意書內容，並同意參與問卷調查。

參加者簽署：_____　　日期：2019 年_____月_____日

基本資料

1.	照顧者年齡：	
2.	照顧者性別：	☐男 ☐女
3.	被照顧者年齡：	
4.	被照顧者性別：	☐男 ☐女
5.	居住地區：	☐深水埗 ☐長沙灣 ☐大角咀 ☐黃大仙 ☐觀塘 ☐其他：_____
6.	你是被照顧者的：	☐配偶 ☐子女 ☐媳/婿 ☐兄弟/姊妹 ☐親屬 ☐其他：_____
7.	照顧年期：	_____年至今／_____至_____期間
8.	平均每星期的照顧時間：	_____小時
9.	你是否家中唯一照顧者？	☐是 ☐否
10.	照顧者健康狀況 (可選多項)： i) 照顧者有沒有慢性病？☐沒有 ☐高血壓 ☐高膽固醇 ☐糖尿病 ☐白內障 ☐青光眼 ☐關節炎 ☐骨質疏鬆 ☐心臟病 ☐氣喘 ☐中風後遺症 ☐腦退化症 ☐腎病 ☐前列線炎 ☐癌症 ☐其他：_____ ii) 照顧者有沒有肢體上的傷殘？☐沒有 ☐有（請註明）：_____ iii) 照顧者是否需要輪椅／助行器？☐沒有 ☐有（請註明）：_____ iv) 你認為自己的健康狀況屬於？ ☐很好 ☐好 ☐一般 ☐差 ☐很差 v) 若照顧者有其他障礙，請列明：_____	

請在以下各問題中圈出您認為最合適答案

照顧壓力評估 - 沙氏負擔訪問 (ZBI)

以下 22 個項目將綜合評估病人對照顧者的情感、社會、身體及經濟方面造成的影響。每項分值 0~4 分，總分為 21~40 分表示無負擔或輕度負擔，41~60 分表示有中到重度負擔。

你照顧腦癇症病患者時出現下列感受的程度：

	從沒有	很少	間中	頗多	經常
1. 你有沒有感到你這親人所要求的幫助過於他/她真正需要的呢？	0	1	2	3	4
2. 你有沒有感到因花了時間在這親人身上，而使自己時間不足夠呢？	0	1	2	3	4
3. 你有沒有因為要照料這親人，又同時要應付家庭和工作上的種種責任而感到有壓力呢？	0	1	2	3	4
4. 你有沒有為你親人的行為而感到尷尬呢？	0	1	2	3	4
5. 當你親人在你附近時，你有否感到忿怒呢？	0	1	2	3	4
6. 你有否感到你親人在你與其他家人的關係上產生負面的影響呢？	0	1	2	3	4
7. 你有否為你親人的將來感到害怕呢？	0	1	2	3	4
8. 你有否感到你親人正依賴著你呢？	0	1	2	3	4
9. 當你親人在你左右時，你會否感到緊張呢？	0	1	2	3	4
10. 你有否感到因為照顧這親人而使自己的健康受損呢？	0	1	2	3	4
11. 你有否感到你親人使你的私人空間不能如你希望有的多呢？	0	1	2	3	4
12. 你有否感到你親人使你的社交生活受到限制呢？	0	1	2	3	4
13. 你有沒有因為你親人的原故，對於請朋友到訪一事感到不安？	0	1	2	3	4
14. 你有否感到你的親人正期望你照料他/她，好像就只有你是他/她所能依靠的？	0	1	2	3	4
15. 你有沒有覺得沒有足夠的金錢去應付你自己及照顧患者的開支呢？	0	1	2	3	4
16. 你有沒有覺得沒你將不能夠繼續照顧患	0	1	2	3	4

者？					
17. 你有沒有覺得自從患者病發之後，你失去支配自己的個人生活？	0	1	2	3	4
18. 你有沒有希望別人能夠代你照顧患者？	0	1	2	3	4
19. 你有沒有感到不能肯定你能為你的親人做什麼事呢？	0	1	2	3	4
20. 你有沒有感到你該為你親人做更多的事情呢？	0	1	2	3	4
21. 你有沒有感到在照料你親人的事上，你其實可以做得更好呢？	0	1	2	3	4
22. 總括來說，在照料你親人上你感到有很大的負擔？	0 無	1 輕	2 中	3 重	4 極重
總分：	/88				

**24 分或以上人士可能會有較大機會患上抑鬱症 (Schreiner et al., 2006)

Appendix B

宏恩基督教學院
腦癇症照顧者生活素質研究
聚焦小組／訪談問題

本研究由宏恩基督教學院社會工作(榮譽)學士四年級同學進行，旨在了解本地腦癇症照顧者的壓力與生活素質，以及探討發展相關支援服務的可行性。

此聚焦小組／訪談內容（包括錄音和筆錄）只限本學系研究人員作統計分析之用，所有資料將以匿名形式保存和堅守保密原則。所進行的研究對訪談者不會有任何負面的影響，受訪者亦有拒絕接受訪問的權利。是次聚焦小組／訪談內容將於完成研究後銷毀。如有任何疑問，請與負責本研究的同學陳凱茵小姐聯絡（電話：65946627，電郵：s1503033@gratia.edu.hk）。

基本資料

1.	照顧者簡稱：	
2.	照顧者性別：	□男 □女
3.	擔任照顧者時間：	

聚焦小組／訪談問題

I. 照顧者狀況

1. 現在你需要做什麼照顧工作？比起以前是越來越多，少了，還是一樣？ 原因為何？

2. 當你有時想或有需要離開被照顧者時，你會找其他人幫忙照顧嗎？會找誰幫忙？原因為何？

3. 若有需要找尋幫助，而你又未能找到合適的幫手，你會如何處理？

II. 情緒狀況

4. 相比以前不用做照顧者時，你覺得自己是比以前開心，現在壓力多了，還是一樣？如果有煩惱，是煩甚麼呢？

5. 你會否覺得做照顧者的壓力很大？有甚麼壓力？原因為何？你會如何處理？

6. 曾否試過當著被照顧者面前，投訴照顧他／她覺得很辛勞？被照顧者有甚麼反應？事後你有何感覺？

III. 社交狀況

7. 你會否經常與朋友聯絡(如打電話，上網聊天)？有多經常？

8. 你會否經常約朋友、鄰居、不同住家人外出？朋友約你外出，你是否多數都會去？為甚麼？

9. 你的朋友、鄰居或不同住家人會否來探望你？有多經常？

IV. 經濟狀況

10. 你覺得家裡的經濟狀況是？

11. 面對經濟壓力，你有甚麼實際行動應付日常生活(縮減飲食開支，找兼職工作，申請政府援助)？

V. 社會資源及服務使用

12. 自成為照顧者後，你接觸過甚麼政府／非牟利機構？(如急症室服務、家務助理、短暫照顧／緊急安置服務、日間照顧服務、復康巴士) 是否經常使用？你從何得知這些服務？

13. 使用服務後，能否減輕你的壓力？如何幫得上忙？

14. 你認為政府或非牟利機構最好能開設甚麼新的服務以符合你的需要，對你有所幫助，或能減輕你的壓力？

Appendix C

宏恩基督教學院
腦癇症照顧者生活素質研究
聚焦小組／訪談問題

本研究由宏恩基督教學院社會工作(榮譽)學士四年級同學進行，旨在了解本地腦癇症照顧者的壓力與生活素質，以及探討發展相關支援服務的可行性。

此聚焦小組／訪談內容（包括錄音和筆錄）只限本學系研究人員作統計分析之用，所有資料將以匿名形式保存和堅守保密原則。所進行的研究對訪談者不會有任何負面的影響，受訪者亦有拒絕接受訪問的權利。是次聚焦小組／訪談內容將於完成研究後銷毀。如有任何疑問，請與負責本研究的同學陳凱茵小姐聯絡（電話：65946627，電郵：s1503033@gratia.edu.hk）。

基本資料

1.	職員名稱：	
2.	職員性別：	□男 □女
3.	職員加入機構年資：	

聚焦小組／訪談問題

I. 職員狀況

1. 你日常需處理那些與腦癇症照顧者相關的工作？

2. 工作能否切合照顧者的需要？原因為何？

3. 依據現時機構的人手編制和資源，你認為足以應付全港的照顧者需要嗎？有何建議？

II. 照顧者狀況

4. 請分享你與病人／照顧者的日常的交流／故事。

5. 依你觀察，照顧者有甚麼壓力？原因為何？他們會如何處理？

6. 照顧者曾否向你／同工求助？求助內容是什麼？你／同工如何提供協助？

III.社會資源及服務使用

7. 你認為現時政策能否照顧到腦癇症病人照顧者的需要？

8. 你認為政府或非牟利機構最好能開設甚麼新的服務以符合同工／照顧者的需要，對同工／照顧者有所幫助，或能減輕同工／照顧者的壓力？

Appendix D

Interview Transcript of Adam, Father of 6 and 7 years-old epileptic sons

Date: 16/04/2019

Time: 7:30 p.m. - 8:30 p.m.

Venue: Tuen Mun

Attendees: Student Worker (SW), Adam (A)

Duration of Recording: 60 minutes

W: 你好，我是宏恩基督教學院社工學系四年級學生陳凱茵。多謝你願意抽時間出席面談，今次研究目的是了解腦癇症患者、家人和照顧者生活質素。今次邀請是想你分享你作為照顧者的故事，以便我和公眾了解照顧者切身的需要。你想我怎樣稱呼妳呢？

A: (微笑) 可以叫我 Adam。

W: 好啊，Adam。今次面談就分為五部份，我們先從照顧者狀況開始吧。現在你需要做什麼照顧工作？

A: 早上六點早上起來，我就要先煮早餐和午飯給我六歲和七歲大的兒子。因為上課時間是九時至下午三時二十分。所以我要盡快幫他們梳洗、更衣，然後再送我兩個兒子去特殊學校。自己再回家再吃早餐，吃早餐都真是難得清靜、悠閒的時間。中午就收拾家居、為他們準備茶點。下午三時半接他們回家，幫他們洗澡、準備晚餐，到 12 點多便睡覺，其實都唔算好難。

W: 比起以前要做的照顧工作是越來越多，少了，還是一樣？ 原因為何？

A: 其實是多越來越多。第一個原因是發作頻率問題，以前可能哥哥一個星期會發作兩次，但現在他跟弟弟一樣可能一星期都有三、四晚會「抽筋」，兩個一齊抽時都會頗吃力，不知道幫那個才好。隔日他們因為抽筋過後都需要休息，變相第二日都會被迫學校請假。於是第二個原因是要幫他們追上學習進度，就算學習都已經入了調息班，他們缺課時都難免在學習時遇到困難，我就自自然然成為了兩個小朋友的補習老師。所以照顧他們的時間亦比以前多了。

W: 當你有時想或有需要離開兩個兒子時，你會找其他人幫忙照顧嗎？會找誰幫忙？原因為何？

A: 基本上都不會，無甚麼機會可以找到人幫忙，家中又只有我一個。極其量就算找都是找樓下看更幫手望望兩個兒子，有甚麼忘記買的就「快快手手買埋佢」。不過真的沒有人可以幫忙照顧。你明的「男人老狗」都怕麻煩到其他人……(苦笑)雖然我好像是爸爸和媽媽角色都做了，哈哈！不過都坦白說但免得他們「抽筋」嚇到別人，歧視的眼光都令我們作為照顧者挺尷尬和覺得自責，「對唔住人」。（別人的眼光）

W: 若有需要找尋幫助，而你又未能找到合適的幫手，你會如何處理？

A: 呃……(沉思一回)。無辦法之下就一定要「Call 白車」，唯有送佢兩個入醫院。 “Touch wood” 講句，都希望將來不要有這些事發生。你都說得對……

W: (點頭) 我們到了第二部份情緒狀況。相比以前不用做照顧者時，你覺得自己是比以前開心，現在壓力多了，還是一樣？如果有煩惱，是煩甚麼呢？

A: 壓力多了就一定的，有開心都有不開心啦。開心的是見到他們(兩個兒子)有進步，被老師讚他們乖是真的有成功感，起碼他們都受師長喜愛啦哈哈，「唔打得都睇下」。至於是煩惱，他們兩個都一來本身身體不好，二來是我想是我和前妻離婚原因都是有關於兩個小朋友。本來覺得有小朋友來到家中是件很歡恩的事。普通小朋友都可以帶出去行下山，上天下海什麼都可以。但……都無可奈何，家人的關係都比較脆弱。

W: 你會否覺得做照顧者的壓力很大？有甚麼壓力？原因為何？你會如何處理？

A: ……會，當然會覺得壓力很大。第一是自己一個承受照顧工作「永遠做不完」的壓力。第二是都會有時為到自己將來狀況會感到有壓力，我現在年紀不大，但我將來仍然要照顧兩個兒子十年二十年。但都不怕跟你講，我們(照顧者)都有老去的一天，我們的孩子又由誰來照顧呢？想到這裡其實都只可以自我安慰，基本上是處理不到。世上總有這些事是很難跟旁人解釋，有苦說不出。

W: 曾否試過當著兩個兒子面前，投訴照顧他們覺得很辛勞？他們有甚麼反應？事後你有何感覺？

A: 有啊，我試過曾經兩個兒子不肯食早餐，差點返學遲到。回想起來是因為是睡眠不足，身體肌肉成日都無緣無故疼痛得很厲害，又有勞損。我當時就鬧了他們幾句就出了街冷靜一下。冷靜完都是要送他們回學校，我自己回到家落公園做運動。待他們回來後，「度氣過咗」，再「超人打怪獸」。盡量心態調節，有時間就好，可以就跑步減壓。

W: 明白，我們進入第三部份社交狀況。你會否經常與朋友聯絡(如打電話，上網聊天)？

A: 無啦，自從他們出世以後都甚少與原先朋友有聯繫，都是近來才跟兩個兒子的特殊學校中一樣有同樣病(腦癇症)的女兒的媽媽聊過兩、三次天，起碼叫做有人可以「吹兩句，無咁悶」，交流下心得。

W: 你會否經常約朋友、鄰居、不同住家人外出？朋友約你外出，你是否多數都會去？為甚麼？

A: 現在真的不敢和朋友家人出街。有次行街，打算難得輕鬆一下，突然收到學校打來說哥哥抽筋，我即刻由觀塘「飛的」回屯門。但上到的士亦都會想，其實回到屯門哥哥都應該「抽完」。我想如果不需要照顧他們兩個，我可以工作，不用困住自己，社交也多些。不過經過這次後，就算朋友約出來都會找理由推掉，除非別人不介紹我帶兩個小朋友出來。

W: 你的朋友、鄰居或不同住家人會否來探望你？有多經常？

A: 都會來探望的，過時過節例如新年，否則都很少。家人時常都說不介意，但都很少聯絡大家，始終我不是特別出色，我亦生不到令他們驕傲的孫子。

W: 我們來到了第四部份——經濟狀況。你覺得家裡的經濟狀況是？

A: 好困難。香港一個人都生活，加上租金都起碼要八、九千元。我現在三人家庭收入主要都是靠 Home Office、靠積蓄每月哥哥弟弟都要花大約八千元，扣除租金及家庭必要開支，其實都已經所餘無幾。

W: 面對經濟壓力，你有甚麼實際行動應付日常生活(縮減飲食開支，找兼職工作，申請政府援助)？

A: 始終收入有眼，支出又多，學廣告講都真是「慳得一蚊得一蚊」。有時街市都有人不要「菜頭菜尾」，見到都會「問聲可唔可以拎啊靚囡／靚囝」，多數他們都很有人情味。

W: 明白，最後的一部份是社會資源及服務使用。自成為照顧者後，你接觸過甚麼政府／非牟利機構？(如急症室服務、家務助理、短暫照顧／緊急安置服務、日間照顧服務、復康巴士)是否經常使用？你從何得知這些服務？

A: 急症，還有兩個兒子的傷殘金，沒有其他。

W: 使用服務後，能否減輕你的壓力？如何幫得上忙？

A: 哈哈！急症就放兩晚就會被醫生護士趕出院啦。

W: 你認為政府或非牟利機構最好能開設甚麼新的服務以符合你的需要，對你有所幫助，或能減輕你的壓力？

A: 可以獲得額外支援當然是好。我不會妄想自己即刻可以脫離這個(照顧者)身份，如果有機會我都想找個人傾下，但求好像現在一樣，「幾個差唔多遭遇、同聲同氣嘅人去傾傾」，同行者真的很重要。而且，我都想有個自己的空間，暫託機構也好、住宿服務，最好可以就近點、方便點。好讓我日後有更多機會可以繼續做回自己想做的東西，或者重拾我自己最愛的音樂。

Appendix E

Interview Transcript of Betty, Mother of 30 years-old epileptic daughter

Date: 17/04/2019

Time: 3:30 p.m. - 5:00 p.m.

Venue: Shum Shui Po

Attendees: Student Worker (SW), Betty (B)

Duration of Recording: 90 minutes

W: 你好，我是宏恩基督教學院社工學系四年級學生陳凱茵。多謝你願意抽時間出席面談，今次研究目的是了解腦癇症患者、家人和照顧者生活質素。今次邀請是想你分享你作為照顧者的故事，以便我和公眾了解照顧者切身的需要。你想我怎樣稱呼妳呢？

B: 你可以叫我做 Betty，叫我 KK 媽都 OK！

W: 哈哈，你好啊 Betty。今次面談就分為五部份，我們先從照顧者狀況開始吧。現在你需要做什麼照顧工作？

B: 我女兒就依家就 30 歲，佢係 11 歲時發病有腦癇症。平日我早上七點起床，我就要先煮早餐給我女兒吃，幫她刷牙、洗臉、換衣服，帶她到樓下散步。需要覆診時就覆診。中午就看看電視，幫她做復康運動。夜晚就準備晚餐，洗澡。「執頭執尾」後就和她一同同床睡覺。

W: 比起以前是越來越多，少了，還是一樣？ 原因為何？

B: 越來越多。第一個原因是最近 KK 轉藥，因為發現原先的藥令到她有很嚴重的便秘問題。而轉藥期間也令她在警覺性及集中精神方面有困難，變到我要整天要保護她的安全。有時她不睬我，也不知是不是『小發作』（即短暫地失神）。第二原因是情緒和行為問題，醫生都曾說她有自我傷害行為，例如會扯脫自己頭髮去表達自己肚餓，不喜歡食菜又會發脾氣等等。因為她和我們普通人不同，她想我們去明白她，不懂用口去表達，唯有就用手來表達。有時都要花好多時間、耐性去了解女兒想要甚麼、不想要甚麼。

W: 當你有時想或有需要離開女兒時，你會找其他人幫忙照顧嗎？會找誰幫忙？原因為何？

B: 我曾經有試過叫隔離(鄰居)黃太幫手看看 KK，KK 最初都有尖叫、打人啊，但現在我行開半個鐘、一個鐘都可以的。不過坦白說不是人人都有這個愛心，不用有色眼鏡望腦癇症病人，有些人說起話上來都真的挺難聽。（別人的眼光）有些人說，『有沒有搞錯！她會抽筋你都帶她上街』，但他們(腦癇症病人)和我們(照顧者和家長)都需要認識新朋友、社交。

W: 若有需要找尋幫助，而你又未能找到合適的幫手，你會如何處理？

B: 都要靠自己。有時別人不是不想幫，當我自己照顧了她那麼多年時都有時覺得不知所措，那麼就知道有些時要處理上來不是那麼簡單。我有時都會好無力、很無助。無辦法下，我自己又有情緒就會安排 KK 到殘疾院舍暫宿數天，但每次我都會好內疚……

W: 我們到了第二部份情緒狀況。相比以前不用做照顧者時，你覺得自己是比以前開心，現在壓力多了，還是一樣？如果有煩惱，是煩甚麼呢？

B: 壓力多了。(流眼淚)……

W: (拿出紙巾安慰)

B: 多謝妳。原先因為我老伴過身，我開始「諗唔開」，好想「死咗佢好過」。早排我中風入了醫院，嚇到 KK 半死。當時有病不敢留院治療，最後社工跟我說我只有兩個選擇可以安置她，一是入急症室，二就去私營院舍，最後我就請人幫我帶她入院舍。我煩惱是我都年紀老邁，身體不聽話， 成日都為了自己慢慢沒有能力照顧她而擔心、流眼淚……什麼都不由得我去控制，好怕她沒有我會怎麼辦……

W: 你會否覺得做照顧者的壓力很大？有甚麼壓力？原因為何？你會如何處理？

B: ……會，當然會覺得壓力很大。我真的有想過逃避，跟 KK 抱在一起跳樓自

殺就算。

W: 曾否試過當住女兒面前，投訴照顧他們覺得很辛勞？他們有甚麼反應？事後你有何感覺？

B: 有，那時 KK 入學一年級，寫一個字，她寫得很辛苦，我以為她不懂以為她懶惰，忟到死，成日說她不肯做，她見到那麼生氣就不斷哭了。初初怎打得落手呢？大力關上門，鄰居問說你怎麼了，我說我要透透氣，就讓她哭一會兒，要不然我會打死她了。

W: 明白，我們進入第三部份社交狀況。你會否經常與朋友聯絡(如打電話，上網聊天)？

B: 很少。最多都是在公園跟人聊聊天。

W: 你會否經常約朋友、鄰居、不同住家人外出？朋友約你外出，你是否多數都會去？為甚麼？

B: 以前我好鍾意打麻將。但現在很難騰出時間。身邊的人無法理解你在家裡要面對的事情。「有頭髮邊個想做癩痢」，雖然好羨慕身邊的人有一個「正常」的生活，但空到時間出來都情願「補補眠」。

W: 你的朋友、鄰居或不同住家人會否來探望你？有多經常？

B: 我先生的妹妹都尚且會來探我，大概半年一次。

W: 我們來到了第四部份——經濟狀況。你覺得家裡的經濟狀況是？

B: 好困難。

W: 面對經濟壓力，你有甚麼實際行動應付日常生活(縮減飲食開支，找兼職工作，申請政府援助)？

B: 政府有給傷殘金。平日我都會在家煮飯，我都甚少出外食飯。

W: 明白，最後的一部份是社會資源及服務使用。自成為照顧者後，你接觸過甚麼政府／非牟利機構？(如急症室服務、家務助理、短暫照顧／緊急安置服務、日間照顧服務、復康巴士)是否經常使用？你從何得知這些服務？

B: 政府方面，我曾經有排過中度弱智人士宿舍，但到現在都是毫無音訊，社工都跟我說一般要 10 年以上。住宿暫顧服務我都有試過五、六次，可以暫時「拎走」KK。早幾年我都曾經是啟迪會會員，不過想找個人傾訴都沒有。我沒有獲得支持，也真的不知道有任何地方或任何人可以幫助我。

W: 使用服務後，能否減輕你的壓力？如何幫得上忙？

B: 字面上來說是可以讓我稍作喘息，但其實治標不治療本。

W: 你認為政府或非牟利機構最好能開設甚麼新的服務以符合你的需要，對你有所幫助，或能減輕你的壓力？

B: 首先第一樣是對我們照顧者的情緒支援。我們好像透明一樣，沒有人明白我們的感受，照顧者和被照顧者一直都留在互相消耗的惡性循環入面。

Appendix F

Interview Transcript of Ms.Ki, Former staff of Enlighten – Action of Epilepsy

Date: 13/03/2019

Time: 3:45p.m. - 4:30 p.m.

Venue: Tsim Sha Tsui

Attendees: Student Worker (SW), Ms. Ki (K)

Duration of Recording: 45 minutes

W: 你好，我是宏恩基督教學院社工學系四年級學生陳凱茵。是次研究[目的]是了解腦癇症患者、家人和照顧者生活質素。今次邀請你，是想你表達作為於啟迪會前職員的身份，從職員角度去了解服務使用者。妳想我怎樣稱呼妳呢？

K: 你可以稱呼我阿 Ki。

W: 阿 Ki 你好。請問你加入機構工作年資為？

K: 我加入機構大約兩年，主要做 Marketing (市場營銷) 和 PR (公共關係) 工作。但我們算是個比較細的機構，所以有時除了要舉辦活動給外面的公眾參加、認識腦癇症之外，我們都會去做不同活動給 Members(會員) --- 即有腦癇症嘅 Patient (病人) 和他們的家人參加。除了這些工作之外，我有時亦會幫社工一同做 Casework(個案)工作。

W: 明白。你覺得你曾經做 PR 或 Marketing 的工作入面，例如活動設計，可不可以切合到服務使用者需要呢？為甚麼？

K: 以我認識嘅 Members(會員)和照顧者，其實他們最需要的可能是與一班有共同 Situation (情況)的人去一齊聊天。可能是一些聚會啦、參加活動、家庭同樂日，讓他們認識多點同路人。但因為我們(機構)比較細規模(只有兩個前線職員) 。所以我們未必可以時常有 Group Discussion(小組討論)供他們分享現時面對的困難，或者一個 A Patient(病人)之前有這個困難，B Patient(病人) 都同樣經歷當中，他想知道怎樣去解決，但我們就未必有這麼多機會做到。相反我地會投入好多 Effort(功夫)去做類似社區中心的活動，(例如)興趣班、BBQ 活動等。

W: 明白。所以你覺得切合到服務使用者的需要嗎？

K: 切合不到。始終他們其實需要是聊天(分享)。始終有不同家長都曾向我提過想要的小組討論，8-10 人左右，大家可分享困難或一些和解決方法。

W: 依據現時你得知機構的人手編制和資源，你認為足以應付全港照顧者的需要嗎？

K: 一定是不足(苦笑)。因為說白的，先別說滿足全港，可能對於我們機構七百至一千個會員，我們也不是 100%熟悉全部會員。因為有些(會員)基本上需要的服務並非參與活動，他們純粹想有人會 Follow up (跟進)他們的 Situation (狀況)、病情，想找人聊天等。當這些(行動和期望)都未必做到的時候，更不要說服務全港，因我們亦沒有 Approach (主動接觸) 他們和到不同醫院找這些 Case (潛在個案) 出來。我們純粹在網上呼籲(腦癇症患者和家人) Join(加入)機構，或者有空時會到社區，例如到商場「擺 Booth」(設置攤位)，讓他人認識我們機構。如果我們沒

有主動接觸，單純讓人留在這個留意，其實沒有人會留意。這是因為通常身邊朋友有腦癇症，才會上網搜尋，發現這間機構。即使我們曾到醫院外展，我們只會到日間診療大樓的兒科。先要等待護士給 Neurology (腦神經科)的覆診 Name List (人名單) ，我要先留意(名單上的)名字、審核那個人是否患有腦癇症、走過去跟他聊天，然後再介紹機構。而我覺我這個方法是比較笨拙的，始終要自己「去估」、「去撞」那個人是否我需要的目標。還有問題是目標不單是腦癇症小朋友，我們好像忽略了成人那一群，因為成人可能才是正正需要更多服務的目標群體，始終小朋友有家長照顧。那麼成人(腦癇症患者)呢？成人有些不一定出生就有(腦癇症)，有些可能是在青春期途中突然患有腦癇症，那麼這群人是否不需要服務呢？我們好像忽略了這個目標群體，所以我認為不能應付到全港病患的需要，亦不能應付全港照顧者的需要。

W: 明白，接著下來的第二部份是關於照顧者狀況，請分享你最印象深刻、與病人／照顧者的日常的交流／故事。

K: 我最印象深刻的是我離開機構半年前，我們做了大概三個月的小組，主要是以照顧者為主。當時才跟一個比較熟絡的家長，她直至在小組中才透露她之前消失了的一段時間是因為「諗歪咗」，她走了一條輕生的路，後來她當然是沒事。但我發現我們雖然很熟悉，但忽略她們最深層的想法。表面上她很照顧女兒，但當刻我很驚訝，我心想我們是否可以多一點服務呢？如果我們多點服務就會多點知道照顧者最深層的想法，所謂「救得一個得一個，幫到一個得一個」。因為那名媽媽曾說如果沒有這個小組，她會再做一件令她女兒沒有了媽媽的一件事。

W: 依你觀察，照顧者有甚麼壓力？

K: 我認為除了照顧小朋友的問題外，我相信必定是辛苦。因為你不知道患者何時會「抽筋」，也不知道他們的身體何時會變差。而最大的問題是周圍人的歧視目光，這樣亦是照顧者我訴說這是最大壓力和最難受的東西。有名家長曾對我說到她有兩名患有腦癇症的小朋友，有次出街時兩個小朋友同時「抽筋」，她「捉住個大，同時要睇住個細」。她聽到旁人說「啊傻仔，傻仔，傻仔」，當下他很難受。她跟我說畢後，我也看見她「眼濕濕」。我自己都會覺得如果我是那名母親，我都會覺得很難受。因為沒一個家長是想自己的小朋友會被別人嘲諷，他們也想自己小朋友是健康，所以我認為作為家長最大壓力一定是別人的眼光、別人難聽的說話。

W: 總括而言，即是照顧患者分身不暇和別人的眼光是最他們在意。那麼他們當時會如何處理，除了捉住小朋友外，還有其他的後續處理嗎？

K: 如果是「抽筋」，都只是給予患者去休息和恢復體力，當時媽媽都是做這件事。但對社會上的歧視眼光，他們亦都只是默默地忍受。因為即使他們的小朋友被同學欺凌，就算跟學校說也是沒用，同樣的事也只會不斷發生，對這些事亦只可以默默忍受。

W: 那麼照顧者曾否向你／同工求助？

K: 與其是求助，倒不如說純粹是傾訴。他們(照顧者)不會說「請你幫我…」，他們不會也不會請我們「可唔可以寫封信同學校講啊」。他們只期望有人跟他們「傾心事」，主要是傾訴，希望有人會聽他們的故事，有人會聽他們在想甚麼。

W: 同工試過用甚麼方法提供協助？

K: 在我工作的兩年間，說真的以我認知的輔導服務十分不足。我不能說人手不足的問題是個最大的藉口。因為我覺得作為服務人面，我們應主動 Approach (接觸)。就算他是高危的 Members (會員) 或照顧者，都需要跟他們聊天。而不是得知他們發生了一點事，知道他的狀況不好才跟他聊天。相反這就是我們機構一貫的運作模式——「我知道他近來有事，過得不好，所以我才找他聊天」。一來我們不會作主動，二來我們也不會定期舉辦小組，所以我認為這是一樣十分不好的東西。

W: 我們去到社會資源及服務使用的問題，你認為現時政策能否照顧到腦癇症病人照顧者的需要？

K: 現時社會政策基本上是沒有的。就算是醫院服務，沒有一個特別的政策是腦癇症病人和他們的家長。即使是申請資助或傷殘症，也會被醫生或申請核對時也會被他們刁難。因為有些患者並非不能工作，而是純粹在工作途中發作，但這就變得非常具爭議。因為有些會暈倒，他們真的不能工作，之後真的會影響他們以後的工作(仕途)等。然而沒有一個真正的政策幫到他們(患者和照顧者)。

W: 你認為政府或非政府機構最好能開設甚麼新的服務以符合同工／照顧者的需要？

K: 以我所知，有很多非政府機構都會變成了商業模式。他們忽略了作為非政府機構，服務對象並非買賣的生意。非政府機構忽略了他們原來是提供服務給主要想服務的目標群組，好像我們的對象是腦癇症。忽略了輔導服務、職業輔導，接下來我認為需要的是要去聆聽目標群組他們需要些甚麼，而是提供相對的服務給他們。而不是一般社區中心「我有十個興趣班，你哋參加啦，有需要再搵我」，現在不是到診所掛號看病。因為他們參加這個「會」(機構)就證明他們有這個需要。我們要主動照顧他們，而不是等待他們「有事」的時候才幫助他們，因為都不知道那時候會發生甚麼事。

W: 若果是減輕照顧者的壓力呢？

K: 我認為是讓他們去學識一個新技能，因為很多家長用了大半生去照顧他們的小朋友。他們在一天二十四小時，只有洗澡、吃飯的時間，其餘都是照顧小朋友，好像沒有了人生方向。我認為要讓他們學識新技能，可能是工作，或教他們一個新語言也是需要的。不要讓他們長期沈溺在照顧模式中，這是對他們不健康的，要讓他們發掘自己的另一面。而不是二十四個小時中，有二十二、二十三個小時都照顧小朋友，令他們都有第二個身份。

References

Barcaccia, B. (2013). *Quality Of Life: Everyone Wants It, But What Is It?*. Forbes/Education.

Bauman, E. M., Haaga, D. A., & Dutton, M. A. (2008). Coping with intimate partner violence: Battered women's use and perceived helpfulness of emotion-focused coping strategies. *Journal of Aggression, Maltreatment & Trauma*, *17*(1), 23-41.

Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Jama*, 307(4), 398-403.

Collins CE., Given BA. & Given CW. (1994) Interventions with family caregivers of persons with Alzheimer's disease. The Nursing Clinics of North America 29(1): 195-207.

Charmaz, K. (1990). 'Discovering'chronic illness: using grounded theory. *Social science & medicine*, *30*(11), 1161-1172.

Cramer, J. A., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meador, K., & Hermann, B. (1998). Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia*, *39*(1), 81-88.

Diener, E. (1984). Subjective well-being. *Psychological bulletin*, *95*(3), 542.

Enlighten - Action for Epilepsy. (2019). What We Do. Retrieved February 10, 2019, from http://www.enlightenhk.org/

Fisher, R. S., Boas, W. V. E., Blume, W., Elger, C., Genton, P., Lee, P., & Engel Jr, J. (2005). Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia*, *46*(4), 470-472.

Folgheraiter, F., & Raineri, M. L. (2012). A critical analysis of the social work definition according to the relational paradigm. *International Social Work*, *55*(4), 473-487.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of health and social behavior*, 219-239.

Guo, W., Wu, J., Wang, W., Guan, B., Snape, D., Baker, G. A., & Jacoby, A. (2012). The stigma of people with epilepsy is demonstrated at the internalized, interpersonal and institutional levels in a specific sociocultural context: findings from an ethnographic study in rural China. *Epilepsy & Behavior*, 25(2), 282-288.

Higgins, J. E., & Endler, N. S. (1995). Coping, life stress, and psychological and somatic distress. *European journal of personality*, *9*(4), 253-270.

Hodge, S., Lieberman, L., & Murata, N. (2017). *Essentials of teaching adapted physical education: Diversity, culture, and inclusion*. Routledge.

Hui, A. C., Lam, J. M., Wong, K. S., Kay, R., & Poon, W. S. (2004). Vagus nerve stimulation for refractory epilepsy: long term efficacy and side-effects. *Chinese medical journal*, *117*(1), 58-61.

James, E., Hughes, M., & Rocco, P. (2016). *Addressing the Needs of Caregivers at Risk: A New Policy Strategy*. Health Policy Institute.

Karakis, I., Montouris, G. D., Piperidou, C., San Luciano, M., Meador, K. J., Cole, A. J. (2014) Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. *Seizure*, 23 (1): 47-54.

Kim, H., Chang, M., Rose, K., & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of advanced nursing*, 68(4), 846-855.

Lee, M. M., Lee, T. M., Ng, P. K., Hung, A. T., Au, A. M., & Wong, V. C. (2002). Psychosocial well-being of carers of people with epilepsy in Hong Kong. *Epilepsy & Behavior*, *3*(2), 147-157.

Link, G. (2015). The administration for community living: programs and initiatives providing family caregiver support. *Generations*, 39(4), 57-63

Monin, J. K., & Schulz, R. (2009). Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and aging*, *24*(3), 681.

Monroe, S. M., & Simons, A. D. (1991). Diathesis-stress theories in the context of life stress research: implications for the depressive disorders. *Psychological bulletin*, *110*(3), 406.

Noelker, L., & Bowdie, R. (2012). Caring for the caregivers: Developing models that work. *Generations*, *36*(1), 103-106.

Nuhu, F., Yusuf, A., Akinbiyi, A., Babalola, O., Fawole, J., Sulaiman, Z., & Ayilara, O. (2010). The burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital, Kaduna, Nigeria. *Pan African Medical Journal*, *5*(1).

Ozyesil Z., Oluk A. & Cakmak D. (2014) The prediction level of caregiver burden on caregivers' state-trait anxiety levels. *Anatolian Journal of Psychiatry*, 15:39-44

Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of health psychology*, *12*(1), 89-102.

Riessman, F. (1965). The" helper" therapy principle. *Social work*, 27-32.

Sigelman, C. K., & Rider, E. A. (2014). *Life-span human development*. Cengage Learning.

The Hong Kong Council of Social Service. (2019). List of Organization. Retrieved February 10, 2019, from http://dss.hkcss.org.hk/ngo_list.php

Thompson, S. N. (2009). Coping styles of African American youth living in poverty: Understanding the role of coping in resiliency. College of Liberal Arts and Social Sciences Theses and Dissertations.

Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: caregiver coping and making sense of illness. *Aging & Mental Health*, *18*(5), 600-609.

World Health Organization. (2017). *Atlas: country resources for neurological disorders – 2nd ed.* Geneva: World Health Organization.

Zarit S.H., Reever K.E., Bach-Peterson J. (1980). Relatives of the impaired elderly: correlated of feelings of burden. *Gerontologist*, *20*, 649-655.

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