Caring is Not a One Man Show”: Family Caregiver’s Experiences in Caring the Dependent Elderly in Brunei Darussalam

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ABSTRACT - Advanced in healthcare technology, medical sciences and health care system have resulted in considerable prolongation of life. Ageing population is increasing globally. An old age is a period of the individual suffers losses in physical appearance, strength, role and status, which resulted in increase on their disability and physical illnesses. Non-communicable diseases (NCD) contributes to factor causing elderly to become dependent. Consequently, this demands the caregiver to care and assist with their daily activities.

To explore the experiences of family caregiver in caring dependent elderly in Brunei Darussalam. This qualitative descriptive study employed phenomenology approach. Interviews with eleven family caregiver of dependent elderly were conducted from 2017 to June 2018. Interviews were transcribed verbatim and thematic analysis was performed.

Data analysis revealed three main themes. This includes; The demands and cost of caring, Cultural expectation and obligation and finally, Coping mechanisms and strategies.

Caring for dependent elderly by family caregivers has both positive and negative impacts and considered a burden to them. This study highlighted the importance of family involvement, the support from others and various coping mechanism used to cope with their caring duties in caring for the dependent elderly.

Keywords: informal caregiver, family caregiver, family carer, dependent elderly

1. INTRODUCTION

Recent phenomenal advances in healthcare technology; medical sciences and health care system have resulted in considerable prolongation of life (da Costa Melo, dos Santos Rua, and de Brito Santos, 2014). Brunei Darussalam is not exceptional. In Brunei Darussalam, the life expectancy is 78 years for female and 76 years old for male (Ministry of Health, 2015). Looking at the statistic in 2015, it was recorded that out of 417, 2000 people, 7.2% were aged 60 and above (Ministry of Health, 2015). Further, according to Department of Economic Planning and Development, Brunei Darussalam, they estimated that the sultanate would continue to witness a rise in its ageing population (New Brunei Daily, 2018). The number of elderly by 2050 will rose to 168,058 (Brunei Darussalam Country Report, 2014).

Elderly based on most developed countries are defined as those at the age of 65 years old and older. However, the United Nation (UN) agreed that the age of 60 is considered the beginning of old age or when a person received the pension benefit (World Health Organization, 2017). Similarly in Brunei Darussalam the retirement age for civil servant and age for receiving Old-age pension is 60 years old (Brunei Darussalam Country Report, 2014).

Boyacioglu and Kutlu, (2016) suggested that an old age is a period when an individual suffers or losses their physical appearance, strength, role and status, and become dependent with an increase in disability and physical illnesses. Moreover, chronic illnesses such as diabetes, heart diseases and stroke were also mostly seen among the elderly and this consequently contributes to dependency on care giver amongst the elderly (Xie et al, 2016).

It was found that primary caregiver experiences in caring for the dependent elderly have an impact on their quality of life. This is because caregiving demands a significant amount of time and energy (Sakakibara, Kabayama & Ito, 2015).

A study in 2011 found that primary care giver are physically, mentally (psychological or emotional), socially and also financially affected (Barbosa, Figueiredo, Sousa, and Demian, 2011). A much recent study in 2016 by Grun, Pieri, Vaillant & Diederich posited caregiver reported feeling that care giving creates a burden

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or strain on them. Similar finding was also echoed in other previous studies (Jaracz et al 2015, Yu et al 2015, Bastawrous 2012 & Bleijlevens et al 2014).

A study that explores the diversity of the experiences of family caregiver of older adults with multiple chronic condition in Canada (Williams et al, 2016) found that the primary caregiving often result in sacrifices of their own health and well-being especially those who had multiple chronic condition (MCC) such as dementia. This is because the care of such elderly requires extensive care from the primary caregiver. This resulted in significant burden of care and burnout to the caregiver, which consequently causing emotional exhaustion and reduced personal accomplishment (Truzzi et al, 2012).

Other impact experienced by primary caregiver secondary to the caring task includes feeling of stress (Luchesi, et al, 2016), lowered level of well-being and poor physical health (Williams et al, 2016), increase risk of depression and anxiety (Truzzi et al, 2012; Williams et al, 2016) and increased morbidity and mortality (Truzzi et al, 2012). It can be argued that this is because the caring task demanded full commitment from the career. Hence, caregiver has less time for leisure. Subsequently, this has an impact on their daily life and requires them to make adjustment (Losada et al, 2010).
The positive impact and challenges faced by the caregiver, there are also studies that reported the positive aspects of giving care. This includes self-satisfaction, reciprocity and sense of duty having been fulfilled (Xie et al, 2016).

**Caring for elderly in the context of Brunei Darussalam:** Despite, being a multi-ethnic society, three-fifths of the population of Brunei Darussalam, a Sultanate in SE Asia are Melayu or Malays. Islam, being the national religion of Brunei, dominates and influences the everyday life of the population. While 67% of the population is Muslim, Brunei also welcomes other religion to be practiced in the country (Brunei Darussalam Statistical Yearbook, 2010).

Culturally, the responsibility for looking after the elderly is placed on the shoulder of the children and immediate family members. The extended family system practice in this country facilitates the process (Brunei Darussalam country report, 2014). Similar culture is also shared with the Thai (Wongsawang, Lagampan, Lapvongwattana and Bowers, 2013), Chinese (Xie et al, 2016) and Turkish (Boyacioglu and Kutlu, 2016).

The responsibility of the family particularly, children in caring for the elderly are also legal in Brunei. According to Islamic Family Order, section 184 of the Syariah law, children are required to look after their ageing parent. This is not limited only to provision of monetary assistance but also extends to providing care to them. If fails, despite the childrens’ ability to provide the care and support, a legal action can be taken against them (Mat Sani, 2016).

To date, there are no studies on the experiences of family caregivers in caring the dependent elderly, particularly in Brunei. This created a gap in the knowledge and therefore has fueled the need to embark on this study. It is hope that this study could assist policy makers in developing strategies, services and support system requires by the family caregivers.

The study aims to explore the experiences and challenges faced by family caregivers in caring for dependent elderly.

## 2. MATERIALS AND METHOD

A qualitative research design adopting the descriptive phenomenology approach has been applied in this study. Individual semi-structured interviews held at the participant’s homes or workplaces were conducted. This was seen as most natural, convenient and appropriate setting and it helps to ensure comfort and privacy to participants (King & Horrocks, 2010).

The inclusion criteria of this study include he/ she must be a family member of the dependent elderly and actively provide the care for the elderly for at least one month. The participant must also be 18 years old and above. Whilst, domestic helper, part time carer, paid caregivers and voluntary careers were not included in this study.

Participants were recruited via snowballing and purposive sampling. This is deemed as appropriate as it
targets specific group of people to meet the conceptual and substantive needs of this research (Polit and Beck, 2012). This resulted in a good mixture of participants coming from various socio-demographic background. Interviews were stop upon achievement of saturation point, in this case it was after the tenth interview.

The first interview was done by one of this study team member whom was an undergraduate student under the supervision of one of the trained researcher in the team. The remaining interviews were mostly done by the student himself without supervision as the team agreed that he has got the skill to conduct the interview. Participants’ comfort and confidence in the data collection as well a capacity to represent their sense of self (Wallin & Ahlström, 2006) was enhanced in this study by allowing them to undertake interviews in the language of their choice. Transcription and analysis were also conducted in the source language as suggested by Twinn (1997) as particularly appropriate in cross cultural research in order to reduce risks of loss of meaning which may be associated with translation. According to Lincoln & Guba (1985) this is one way of maintaining internal validity or rigour in qualitative research especially those involving different languages. Translation of the excerpts was only done for the purpose of writing this research finding.

Analysis

Copies of the transcripts were distributed to all research members to analyse individually. Apart from the student, the other three members of this study have extensive experiences in conducting qualitative research. During the analysis process, all members looked for codes and themes. The findings from the individual analysis were compared and discussed further in a group meeting with all the team members to identify common categories and themes. These themes and categories were then discussed and agreed by all of the research team before it was finalised. This helps to enhance the rigour of the study (Birks & Mills, 2011). Relevant excerpts are shared to support the themes chosen, with no actual details of patient are disclosed. Only pseudonyms are used.

Ethical Consideration

Ethical approval was given by the University Research Ethics Committee (UREC) Universiti Brunei Darussalam. Written informed consent was obtained from all participants. Privacy, confidentiality and anonymity were ensured throughout the research.

3. RESULTS AND DISCUSSION
THE DEMANDS AND COST OF CARING

The need for 100 percent commitment

Participants shared that they have to manage their time well between their own family, work and caring for their parent. They revealed that caring takes a lot of time and therefore regarded it as a full time commitment.

“…it similar like working… need hundred percent commitment… everything needs to be taken care of such as eating and drinking, shower, changing diapers because sometimes less than five minutes the diapers need to be change again…” (Ahmad)

“with her (mother) she need almost everything to be done for her. She cant move, she’s paralyzed, so yeah..everything you have to do for her..so you have to be there with her all the time.” (Fauzi).

As caring demanded full time commitment from the career, lots of adjustment has to be made as shared by Saiful:

“…because we have to take care of her (aunt) we are no longer able to go out as much and attend any wedding invitation or functions”.

Financial cost of caring

Participants also expressed that caring for the dependent elderly does not comes cheap. Majority reported having difficulties especially, for those who are unemployed.

“He (father) gets money from the government for his old age pension but it is not enough because the diapers are expensive. He requires three to four pieces daily and each box will only last for few days!” (Azlina).

“A box of diapers can only lasts for two to three days as we need to change three to four times per day. In a week he needs around four to five boxes and he also requires the ‘Ensure milk’ (special formulated milk)” (Aziz).
Emotional cost of caring
The need to be emotionally strong was shared by majority of the participants. Some shared their dependent parent can be verbally abusive, particularly if they needs are not attended to or delayed.

“If I am a bit late even just a bit, you know to attend him when he called me, he (my father) would scold me! He gets angry mmm but he’s still my father!” (Hakim)

Frustration and stress was commonly shared by all. Participants talked about how caring task can be emotionally challenging.

“Taking care of my mother is difficult and stressful especially when she refused to take a bath and eat” (Rosni)

“My husband doesn’t want to listen the advice from the physiotherapist and occupational therapist and it makes me frustrated..i don’t know, doesn’t it want to get better?” (Sheila)

CULTURAL EXPECTATION AND OBLIGATIONS
Responsibility as an immediate Family Member in Caring
Participants revealed that caring for their dependent parent or family is the responsibilities of the immediate family member. They considered this as a norm and it is expected from them. Sheila, a 59 year old wife shared;

“He is my husband and what do you expect? Well I have to, I have to do it because he is my husband, it is my responsibility to take care of him”.

Children whom are taking care of their dependent parents also shared the above sentiment.

“It is the responsibility of a child especially me, I am the eldest and I felt obliged” (Laili).

It can be noted that despite being able to afford a paid career, it can be seen how participants still prefer and consider immediate family members as the most ideal to provide the caring.

“…for me, as long as I am still capable I don’t need others to help because they don’t understand the needs. If amongst the family member we would understand and know each other well. For me, I don’t want others to take care of my mother” (Azlina)

“…not to be fully dependent on the paid caregiver. The family members should be the one because they are their family” (Maidi)

Being a role model for other family members
Participants shared that by caring for their parent; they are indirectly setting up good example to their children and siblings.

“I told them one day your kids may hire the caregiver when you are old (sarcastic tone). They need to see the example from us so and they will follow in future” (Ahmad).

Participants also expressed how they passed on the tradition of looking after their older family member to the younger generation hoping that it would continues. A way used to do this is by involving their nephews and nieces in delivering the care.

Ahmad shared that:

“I involved my nieces and nephews and explained to them so that they can understand their role as family members so they will not be dependent on the paid caregiver”.

Caring as a way of showing appreciation
Caring for parents were also used as an act of reciprocity; way of ‘paying back’ all the love and care that their parents had for them when they were growing up. They cared for their parents to show their appreciation for looking after them when they were younger. This is reflected in the following excerpts.

“He made me what I am today” (Azlina).

“If it’s not her, I won’t be here. She cares for me well, sent me to school to university and now it’s my turn to look after her” (Sheila)

COPING MECHANISMS AND STRATEGIES
Considering the impact and demand that the caring task requires, various ways of coping were shared by the participants. This ranges from the use of religious approach and support from family, government and
NGOs.

Using religious approach as a way to cope
An example of the use of religious approach as a way of coping with the challenges is shared below.
“…I always pray ‘God’ please …give me the strength …so I will be able to continue taking care of my mother…” (Azlina).

“If it felt too much to handle, I just try to calm down and pray” (Syukri)

Meeting financial demand
In optimizing the care with their minimal financial resources, participants shared their strategies in meeting needs with the limited budget.

“We split among family members (money), we also go abroad to Miri (East Malayis, border to Brunei) to buy diapers since the price is cheaper…” (Ahmad)

“All of us (siblings) contributed some money towards buying all the necessities required for him (father)…” (Hakim)

Making use of the help and support from family, government and NGOs
Many participants reported that the responsibility in caring for the dependent elderly should not be left on an individual. They strongly verbalizes that it requires teamwork and assistance from everyone in the family and others too.

Everyone’s involvement including distant relatives, their employer and the community are crucial in the care for the dependent elderly in the family. This is because as most participants agreed that it is very challenging and demanding task.

“I need two to three people to lift my father to the wheelchair because I cannot do that alone as he is heavy…” (Ahmad).

“I involved my other siblings. Sometimes in the weekend, I asked my nephews to come to my place and help to look after their grandparent whilst I go out to do my weekly shopping” (Rosni)

P05 emphasized on the importance of support from others in delivering care for his father.

“When my husband was admitted to hospital, I felt blessed that I’ve got the support from my employer. She advised me to talk to my in charge so I can get some sort of leniency so that I can leave office to visit him whenever necessary…” (Sheila)

However there are also cases reported by participant where she did not get any support from the other siblings. This has caused a lot of frustration to her as she has to handle and managed the care by herself.

“I’ve got seven siblings altogether. My brothers supposed to help me but most of them doesn’t seem to bother. They seldom visit or called her so all is on me! I only received money from welfare department and I am not working. I have nobody to rely on so it is a struggle” (Azlina)

DISCUSSION
Caring for dependent elderly requires a full hearted dedication and commitment from the careers. Study in 2017, revealed that the level of commitment that is required for this task is equivalent to a full time job (Nortey, Areyetey, Aikins, Amendah & Nonvignon, 2017). Thus, this requires a working carer to manage and divide their time between work and the caring task (Gary, Hahn, Thapsuwan, and Thongcharoenchupong, 2016). Career has to find way to manage their time properly and make use of their family members particularly their siblings and their children to help out with the caring task (Barbosa, et al, 2011; Floriano, Azevedo, Reiners and Sudre, 2012). In a household whereby, all the people from multigenerational households still lives together and shared the responsibilities between them. It was argued that this measures help to alleviate stress (Gary, et al, 2016) and caregiving burden (Grun, et al, 2016; Jaracz et al, 2015; Yu et al, 2015; Bastawrous, 2012; Bleijlevens et al, 2014). Similar finding was echoed in a much recent study in 2017 whereby Mahdavi, Fallah-Khoshknab, Mohammadi, Hosseini & Haghi found that caregivers who spent longer hours to provide care and did not received assistance from other family members suffered from high amount of care strain.

Further, caregiving task also appeared to drain the career emotionally and physically and it causes stress (Truzzi, et al, 2011). Sleep impairement or disturbances, poor health and chronic pain may develops secondary to the stress experienced by these career (Luchesi, et al, 2016). Therefore, it is of paramount importance for career to establish an alteration routine between family members. This allows the primary
Barbosa, et al, (2011) argued spiritual and religious belief have the strong influences among the senior caregivers in caring the dependent elderly. This is reflected in this study whereby, the caregiver keeps referring back to religion as it helps them to calm down and to relieved their stress. Gary, et al, (2016) supported that negotiation between the extremes of bliss and suffering and understanding suffering is part of life as this may help carers to mediate stress and find the meaning in their day to day struggles. Gary et al, (2016) reported that stress amongst the career is mostly due to the unpredictable mood changes of the dependent elderly. Gary et al, (2016) added the mood changes are due to their illnesses and how it has impact their life, in this case, becoming dependence on others.

Providing care to dependent elderly is demanding and challenging, and has an impact on many aspects of career’s life. It is reported that careers’ social activities and life were disrupted (Xie, et al, 2016) and they do not have sufficient time to maintain their social life (Mejia, and Arias, 2016). Consequently, some careers tend to abandon their social life (Cauto et al, 2016).

Financial challenges were also mostly shared by all participants. It is well recognised on how difficult it is for the careers to provide all the necessities required for their dependent elderly. In Brunei, in the attempt to assist its people with their daily financial needs, the government offers “Old Age Pension” for all its residence aged 60 years old and above. However, this study found that as much as its recipients appreciate and feel grateful of this privileges, they also shared their frustration about the rising cost of living in Brunei. Participants revealed that the pension is hardly sufficient and often requires additional amount which in most cases come from the family members. Thus, it is often problematic for those career who are unemployed. In most cases some of them use their savings and some giving up the necessities which result in poor delivery care to their dependent elderly (Nortey, et al, 2017). In turn, this kind of economic pressure will caused psychological burden that lead to anxiety, depression, and other problems in the long term (Xie, et al, 2016). Hence, in our study we found that participants came out with measures on what can be done to reduce the cost, for example by doing their shopping in the neighbouring country, which offers them a better deal.

Despite acknowledging that attending the everyday needs of dependent elderly is demanding and a hard work (Floriano et al, 2012 and Xie et al, 2016) most shared that they look after their elderly as a way of setting a good role model to other family members, especially nephews and nieces. Participants echoed that by doing this, other family members will follow and continue the tradition. Other family members e.g. nephew and nieces were taught on how to care for the elderly by getting them involved in the delivery of the care. This is the mechanism used for training the other family members, so they will be able to care for their parent in the future and also to provide sort of respite care. This is similar to findings in study by Williams et al (2016) whereby they reported feeling happy in taking care of their family members and they see it as an opportunity to give back or discover personal strength (Williams, et al, 2016).

Furthermore, albeit not having equal number of male and female participants, this study found that both genders equally regarded looking after their dependent elderly, in this case, their parents as their responsibility. This contradicts previous studies conducted with the Thai, Chinese, Turkish, Northern Portugal and Iranian family whereby, they identified care giving job as responsibilities of the women (Wongsawang, Lagampan, Lapvongwatanna, & Bowers, 2013; Xie, et al, 2016; Boyacioglu and Kutlu, 2016; Floriano, et al, 2012; Salama and El-Soud, 2012; Casado-Mejia, and Ruiz-Arias, 2016; Nortey, et al, 2017). However, Wongsawang et al (2013) argues now we can witnessed increasing number of men taking the role as informal caregiver for their family (Casado-Mejia, and Ruiz-Arias, 2016). A reason that accounts for this increasing fashion is the shift in the global trend whereby, women are no longer fulltime housewives. Full-time employment complicates the care for the dependent elderly (Barbosa, et al, 2011).

It is also noted religion plays a big role towards shaping this view as well. All of the participants in this study are practicing Islam and as Muslim children they are responsible to look after their parent, especially when they are old (Quran verse 17:23; 17:24 and 31:14). These practices of caring for the elderly seem to be derived from what these participants observed and learnt from the people in their community or from home (Mundigo, 1995). As a child, they grows up seeing their parent function at home, performing roles and responsibilities. Generally, for most, when younger, children would see their parent as role models and feel that they need to emulate them. Subsequently, this influences their understanding of how they have to act and what they should do (Frosh et al., 2002).

Government policy also influences and shapes the participants’ view on the responsibility in caring for their dependent parents. Closer investigation revealed that this tradition was actually further reinforced by the various interventions taken by the government of Brunei. Principal amongst these would seem to be the imposition of Syariah law and also via education at school. Brunei Darussalam as an Islamic sultanate adopted Islam in the 15th Century and since then has had upheld Islam as a way of life. Syariah law has long been embedded in the country’s system of governance with the Malay Islamic Monarchy (MIB)
ideology. However, it was only in May 2014, phase 1 of the new Syariah Penal Code Order, 2013 came into force. According to Haji Hassan Haji Metali, the chief registrar of the Syariah Appeal Court, quoted in Brunei’s newspaper by Mat Sani on June 12th, 2016 (Mat Sani, 2016), children are responsible to look after and support their aging parents. This is written in Section 217 under the Islamic Family Order of the Syariah Law. This does not refer only to monetary assistance; it includes all the basic necessities in everyday life, like food, clothes and shelter.

As an incentive to instil the culture of looking after parents, the government, via the Ministry of Education (MOE), has taken various measures. These include the introduction of various subjects into the school curriculum, both primary and secondary and also in religious schools. One example of this curriculum development involves a subject called Social Studies. These were first introduced in 2009 for students, aged from nine to eleven years old (primary four to primary six). Later in 2012, Social Studies was extended to secondary school students (Year 7 and Year 8). Social studies is an integrated study of subjects drawn from the social sciences and humanities to enable understanding of human interaction with the natural and social environments, as well as the inculcation of Bruneian attitudes and values. According to the Director of Curriculum Development Department, MOE (Social Studies for Brunei Darussalam, Year 7., 2012), it is hoped via this subject, that students will develop an understanding of Bruneian society and culture and therefore, become responsible and civic-minded citizens.

LIMITATIONS
This study only involved a small number of female participants and is homogenous in terms of their race. Further, step to ensure that our interpretation and analysis was true to the participants’ experiences (member checking) was not carried out. This could potentially affect the trustworthiness and credibility of the analysis (Creswell & Miller, 2000). However, various measures have been taken to help to enhanced its credibility.

4. CONCLUSION
The experiences on caring for the dependent elderly by family caregivers have both positive and negative aspects. Primary care giver utilizes various coping mechanisms to cope with their caring duties. This study highlights the importance of family involvement and the need of support not just from family but external organizations, both government and NGOs. This is of paramount importance to ensure the well being of the primary care giver are looked after so that they can continue caring for their dependent elderly.

REFERENCE


