

ORIGINAL ARTICLE

**THE EXPERIENCES AND CHALLENGES IN CARING FOR
HIV/AIDS PATIENTS: A QUALITATIVE EXPLORATION
AMONG MUSLIM FAMILY CAREGIVERS IN
TERENGGANU, MALAYSIA**

**Pei Lin Lua, **Norhayati Mustapha,
***Ramle Abdullah, ^Ahmad Kashfi Abdul Rahman*

**Centre for Clinical and Quality of Life Studies (CCQoLS), Faculty of Medicine and Health Sciences (FMHS), Universiti Sultan Zainal Abidin (UniSZA), Kampus Kota Jalan Sultan Mahmud, 20400 Kuala Terengganu, Malaysia;*

***Centre for Clinical and Quality of Life Studies (CCQoLS), Faculty of Medicine and Health Sciences (FMHS), Universiti Sultan Zainal Abidin (UniSZA), Kampus Kota Jalan Sultan Mahmud, 20400 Kuala Terengganu, Malaysia; ***Faculty of Islamic Contemporary Studies, Universiti Sultan Zainal Abidin (UniSZA), Kampus Gong Badak, 20400 Kuala Terengganu, Malaysia;*

^Department of Medicine, Hospital Sultanah Nur Zahirah (HSNZ), Jalan Sultan Mahmud, 20400 Kuala Terengganu, Malaysia.

Abstract

Objective: The family caregiver has a pivotal role in the management of HIV/AIDS patients and their well-being is consequently crucial as it could impact negatively on the quality of caregiving. This preliminary qualitative investigation intended to explore and describe the challenges and experiences of HIV/AIDS family caregivers in Terengganu, Malaysia. **Methods:** A convenient sample of family caregivers of HIV/AIDS patients who were aware of the diagnosis was enrolled. Recruitment was conducted in Hospital Sultanah Nur Zahirah, Kuala Terengganu, Malaysia and semi-structured interviews were used. **Results:** Results were transcribed into verbatim before being subjected to analysis. Twelve Muslim caregivers consented participation (age range = 18.0 - 81.0; female = 75.0%, mother/wife = 50.0%; married = 83.3%; ≤ primary school = 50.0%; and self-employed = 66.7%). The four major themes that emerged were challenges of caregiving, financial issues, stigma and discrimination, and support for caregivers. Additionally, caregivers did mention several positive aspects of their caregiving role including satisfaction from helping family member and improved family relationships. **Conclusion:** A variety of life aspects were negatively affected by caring for HIV patients, thus requiring a multidisciplinary approach to address such issues. *ASEAN Journal of Psychiatry, Vol. 15 (2): July – December 2014: 120-130.*

Keywords: HIV/AIDS, Family Caregivers, Experiences and Challenges

Introduction

Nearly three decades have passed since the first HIV/AIDS case in Malaysia was diagnosed in 1986. During this period, the disease has spread to all other states in the country. The Joint United Nations Program on

HIV/AIDS (UNAIDS) reported that approximately 34 million people were living with HIV globally at the end of 2011 [1]. Although HIV prevalence in Malaysia is relatively low (0.5%), this actually represents a very large number of people with HIV which

recorded a cumulative total of 94841 and almost 15000 AIDS-related deaths in 2011[1].

Most HIV/AIDS patients have family caregivers who are providing some level of care and support, and they are usually family member or members who care for a loved one with a chronic condition on unpaid basis [2]. Caregivers spend a substantial amount of time interacting with patients in the process of care within a wide range of activities such as housekeeping, personal hygiene, meal preparation, medical care, transportation, financial and moral support [3]. Caregiving is a demanding responsibility as they too could face a number of pressing problems related to patients living with HIV/AIDS. They experienced high level of stress, enormous caring needs and poor health-related quality of life (HRQoL) with the most prevalent factors that cause stress being stigma and discrimination due to disclosure of the disease [4]. In addition, most of the HIV/AIDS affected families are living in poverty and they have to deal with societal discrimination and isolation which can be tremendous psychological burdens [5].

On another aspect, people who experienced stress over the changes in life due to illness were likely to turn to their religions to enable them to feel more comfortable and secure [6]. Consequently, religious beliefs and practices could undoubtedly influence the caregiver's approach in providing care and helped them deal with difficult challenges [7]. Many studies had also explored the role of religion and spirituality in caregiving for patients with chronic diseases such as HIV/AIDS, dementia as well as cancer. For example, Folkman et al., [8] reported that the more religious HIV-positive caregivers experienced less stress and sense of burden compared to their counterparts. Similarly, another study documented that religiosity was also associated with more positive aspects of care giving in African-American caregivers of dementia patients [9].

Although studies have examined the experiences of family caregivers in the United States and Africa, we only know little about the situation in Malaysia, particularly among Malay Muslims in the East Coast of Peninsular

Malaysia region. Muslims represent Terengganu's largest ethnic group, accounting for over 95% of the population [10]. Thus, this article highlights the overall caregiving issue from a qualitative investigation intended to explore the experiences and challenges of HIV/AIDS family caregivers whereby Islam is their major faith.

Methods

Research Design

A qualitative study design was chosen as this was deemed the most appropriate method to generate in-depth knowledge about caregiving for people living with HIV/AIDS (PLWHA). Explorative interviews were used to collect the data but guiding questions were also used to ensure that the care giving experience was investigated in a similar structured manner with each participant.

Participants

Twelve consenting participants were recruited into this study. A purposive convenience sampling approach was performed to recruit caregivers who met the following inclusion criteria: (i) identified as the primary family caregiver. Family caregivers were defined as family member or members who provide unpaid care to a loved one with a chronic condition [2]; (ii) family caregivers who had at least three months' experience caring for their HIV-infected family members, assuming that in this period they would have already been familiar with their responsibilities; and (iii) agreed to participate in the study.

Ethical approval

Ethical approval was first obtained from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (reference: NMRR-12-510-10824 (2)dlm.KKM/NIHSEC/08/0804/P12-564) via online application. Prior to that, the hospital authority was verbally contacted to explain the intention of the study, the period involved, and what was required from the caregivers and hospital staff. Additional discussions were held with the hospital director, the head of Infectious Disease Clinic and the appointed

study coordinator(s) for the purpose of arranging the date and time suitable for caregivers enrolment.

Procedure

Data collection was carried out between April and June 2012. Family caregivers were recruited from the Infectious Disease Clinic, Hospital Sultanah Nur Zahirah, Terengganu, Malaysia.

A month before the study commenced, the staff nurse and researcher identified a list of patients on regular follow-up whose caregivers were aware about their disease. Then, explanations on the study were delivered to patients and they were requested (verbally) to bring their corresponding family caregivers to the Infectious Disease Clinic to participate in the interview during patient's next appointment. On the actual study day (subsequent patient's appointment), all eligible family caregivers who visited the Infectious Disease Clinic were approached at the registration counter and invited for individual face-to-face interview. Verbal explanation on this study was delivered based on a structured Information Sheet. Written consent form was signed upon participation agreement by family caregivers. Once consent was obtained, they were provided with the Caregiver Information Sheet to enhance their understanding about the study.

The subsequent interviews were conducted in the counselling room at Infectious Disease Clinic to ensure sufficient privacy and were audio recorded while non-verbal communication was observed. Each session took approximately 40-50 minutes and was conducted in Malay language (local dialect) which was spoken by most of the Terengganu residents.

The interview questions were open-ended and broad in order to elicit detailed description of the family caregivers' experiences. Nonetheless, participants were also specifically asked about HIV-related medical experiences, social relationships, family functioning, depression and their feelings, problems and needs based on their efforts in providing care to the patients [3].

Data analysis was conducted using the QSR International's NVivo 10 software [11]. Initially, the audio-taped interviews were transcribed into verbatim using Microsoft Word processing programme. The researcher also listened again to the interviews to confirm the completeness of the verbatim transcription. Later, the transcripts were verified and read through again at least three times to identify key themes and patterns arising from the data in relation to the research questions. After that, the data were scrutinized to detect saturation of ideas and recurrent patterns of similar meaning and expressions. The non-verbal cues observed during interviews were additionally noted in the transcripts to facilitate conceptualization of emerging themes.

Results

A total of 12 Malay Muslim respondents were interviewed for this study (refer to Table 1). In this regard, the saturation was achieved at 12 interviews, meaning that adding new people to the sample was no longer producing new potential themes, suggesting the sample size was now sufficient in order to accomplish the study objectives [12]. Nine respondents were female (75.0%) while three others were male (25.0%). The respondents ranged from 18-81 years of age but most were between 18 and 37 years old. Most of the participants had attended either primary or secondary school. The majority identified themselves as self-employed (66.7%) and in terms of their relationship to PLWHA, most were either mothers or wives to the patients.

Table 1. Sociodemographic characteristics of the participants

Variable	No. of respondents	Percentages
Sex		
Female	9	75.0
Male	3	25.0
Age (years)		
18-27	4	33.3
28-37	1	8.3
38-47	3	25.0
48-57	2	16.7
58-67	1	8.3
>68	1	8.3
Marital status		
Married	10	83.3
Single	2	16.7
Level of education		
Degree	1	8.3
Primary school	5	41.7
Secondary school	5	41.7
No formal education	1	8.3
Occupation		
Self-employed	8	66.7
Housewife	1	8.3
Unemployed	2	16.7
Pensioner	1	8.3
Relationship to PLWHA		
Father	2	16.7
Mother	3	25.0
Wife	3	25.0
Husband	1	8.3
Sister	2	16.7
Daughter	1	8.3

(PLWHA = People living with HIV/AIDS)

Five main themes which described the overall experiences and challenges of caregiving for HIV/AIDS sufferers clearly emerged from data analysis. These could be categorised as challenges of caregiving, financial issues, stigma and discrimination, support for caregivers, and positive aspects in care giving.

Challenges of caregiving

Family-based care represented an important element in caring for patients diagnosed with chronic diseases. Caregivers were usually responsible for multiple roles such as patient care, care of dependents and income generation. Their tasks included housekeeping, collecting medications and accompanying patients for medical appointments. The entire

set of challenges was further sub-categorised as (i) ensuring medication adherence, (ii) treatment misconception and (iii) coping with caring.

(i) Ensuring medication adherence

Above all, monitoring drug adherence was most important to them. Every effort was made to ensure that patients adhere to

medications sometimes even involving changes in working schedules and constant reminders to ensure patients continue to consume their medications on time:

If he works, I will phone when it is time for medication-taking. I am worried he would forget to take medication.

(Informant no.3)

My supervisor allowed me to come to the office early (7.30 am) so that I can take a break at 9.30 am. I will rush home to serve medications to my daughter.

(Informant no.11)

When it is time to take medicine, I will prepare the drink and the medicine. After that I will call him. I will wait until he finished taking the medication.

(Informant no.6)

Besides conventional treatment, caregivers also attempted to seek traditional treatment in addition to the current therapy. Interestingly, it was their belief that the illness could have also originated from “bad spirit” interference, hence *ustaz* (religious people) were usually consulted to ward off the spirit:

Sometimes I go and see the ustaz to ask about my mother’s condition. He gave her holy water and it works. But she never misses any of her antiretroviral doses.

(Informant no.4)

After a few times seeing the ustaz and taking HAART, I see a lot of changes in the patient. CD4 has increased and patient is also very healthy and is no longer depressed.

(Informant no.8)

(ii) Treatment misconception

Caregivers understandably need to deal with many challenges. The participants in this study mostly received limited education and the task

of caring for patients had further reduced their time to access the information about HIV/AIDS. Thus, several caregivers mistakenly thought that the antiretroviral drugs were definite cures for their family member’s HIV/AIDS problem:

I thought that HAART can heal illness (HIV) of my son. I am sad when I think of

losing him, but I accepted with an open heart that predetermined fate.

(Informant no.2)

(iii) Coping with caring

Our caregivers’ responses to the question on how they cope with the burden of care were varied, including seeking advice from close family member and avoiding contact with neighbours:

I usually contact my elder brother if I have problems. I feel relieved after talking to him.

(Informant no.1)

My family decided to move from the previous place because we felt better to stay away from them (neighbours). I went to a place where nobody knew us.

(Informant no.9)

However, for many respondents, religious faith was the main source of courage and strength to care for their sick family members. Regular prayers helped them to feel at peace with Allah and to embrace His power of love and care. This is as described by one of the female caregivers:

I pray everyday to Allah. Thank you Allah as I always feel peaceful after each prayer. I can forget the hardship and do the tasks with ease.

(Informant no.3)

Financial issues

Extreme financial constraint was another common experience reported by family caregivers who cared for PLWHA. Subsequently, they had to work harder in order to sustain their family household income, especially when loss of income originated from patients themselves who were the main family breadwinner, resulting in severe financial constraints. Household economic problems became critical when patients began to suffer from frequent HIV-related illness, especially when caregivers were also unable to work because of impending caregiving responsibilities:

My husband has not been down to the sea since two weeks ago because he was sick. I had to stop working after knowing that I was pregnant. I had to borrow money from my siblings to sustain our family expenses.
(Informant no.5)

Caregivers could also incur financial burden from uncovered services such as transportation and home care as well as loss of salaries:

Financial problems made me depressed. I am the eldest daughter and all expenses at home depend on me. Now I had to divide my income to meet household needs and bring my mother to the hospital. Every time I come to the hospital for appointment, I had to provide at least RM100. Sometimes the appointment is twice a month.
(Informant no.4)

Some respondents wanted to work but felt pressured because of their caregiving responsibilities. A female respondent explained that she did informal work for extra income:

It is difficult to find job that is close to home. I had to sell vegetables to meet our household income. All in all, I usually get RM10-15 (USD3 – 5) per day.
(Informant no.7)

Stigma and discrimination

In addition to the above issues, it was also discovered that stigma and discrimination were the major social factors influencing care and caregiving among HIV/AIDS family caregivers. Their experiences of stigma and discrimination were further explained as (i) reaction to the illness and (ii) response to relatives' reactions.

(i) Reaction to the illness

Troubled participants perceived social difficulties and shame that awaited both the caregiver and the care recipient once the patient's HIV/AIDS diagnosis become known. They found it difficult to share the diagnosis with neighbours, friends or even close family members because of the subsequent negative

consequences that could arise e.g: isolation from their neighbours and family members:

I never told anyone about the disease. Some have asked, but I just tell it was TB (tuberculosis). This is because neighbours can still accept if it is TB but not HIV / AIDS.
(Informant no.1)

Relatives and neighbours often reacted negatively once they knew the diagnosis of HIV/AIDS because of fear of contagion:

Neighbours looked down on our family. They hardly talked to us. Some of them passed on the news of our health difficulties to others. Now I feel like I'm in the middle of an island.
(Informant no.10)

Another female caregiver cried when she explained what she had gone through (perceived as stigma):

While my son was in the hospital, she (aunt) came to visit but did not come close to him. When she returned home, all her clothes were soaked in hot water. Until today, she did not even come to our house.
(Informant no.7)

Unfortunately, due to stigma and discrimination, these family caregivers also reported loss of jobs and employment opportunities which further propagated their financial difficulties. One participant contended:

I used to sell local delicacies. My business declined when the neighbours found out my husband was a HIV patient.
(Informant no.9)

Another respondent said:

I know how to bake local delicacies. I want to sell them but I had to cancel my intention. This is because people do not want to buy anything from HIV caregivers. I've seen this happening to my neighbour. So I do not want the same thing to happen to me.
(Informant no.10)

(ii) *Response to relatives' reactions*

Some caregivers had prepared some money for funeral ceremony. This was because they knew the neighbours would not want to help in the event of death due to HIV/AIDS:

I already think and prepare for any consequences in the future. I've saved money for the funeral of my son because I know I will get no help at all from family members, relatives or even neighbours. If they know it is AIDS, nobody will help me to arrange for his funeral. Even worse, they will not attend the 'tahlil' (religious gathering to recite the Holy Quran for funeral). (Informant no.12)

Support for caregivers

Numerous challenges were encountered in the process of caring for HIV patients. Unfortunately, some of the caregivers resorted to providing care in secrecy because of the associated stigma. Their plight would worsen if the diagnosis becomes known by family members, which could lead to diminished support from extended family members. One of the respondents anticipated that she might be isolated if people know of her husband's real health condition:

Who do I turn to for help? I don't want to go about asking people for help because they will want to know the cause of my husband's sickness. I can't imagine if people know he is HIV-infected. I'm sure they will not come to our house. (Informant no.8)

Another male caregiver did not receive any support at all from family members because they had not been informed about the diagnosis:

I will never disclose the diagnosis to anybody. Thus, I get no support from them (relatives and neighbours). I don't mind but I will not ask for help from them. (Informant no.6)

Our findings also indicated that doctors and nurses were the key information resources for family caregivers:

I will refer to the doctors or nurses in the clinic if I have any enquiries or difficulties. I fear of disclosure if I ask others. (Informant no.11)

Positive aspects

Apart from the negative impacts of caring for HIV/AIDS patients, caregivers did mention several positive aspects of their caregiving role including satisfaction through helping their family member and improved family relationships:

I feel satisfied with what I do now. I will not give up and will take care of my daughter until her last breath. (Informant no.2)

My relationship with my brother has improved since I took care of him after being diagnosed with HIV. Recently, he chats with me a lot. (Informant no.5)

I will never regret my decision not to work after graduation because I know my brother needs me more. I will take on this responsibility the best as I can. (Informant no.1)

Discussion

The overall results from our study reflected that family caregivers of HIV/AIDS patients were generally overwhelmed by their responsibilities which had somehow negatively impacted upon their well being and life routine. The overwhelming nature of caregiving activities had also been reported in a few studies conducted in Africa [13-14]. Unlike situations in the Western countries whereby most caregivers were mostly partners or friends, all of the PLWHA in our study lived with their family members. This was consistent with the situation in many Asian countries such as Thailand and China [15-16] in which the family institution generally provides practical and emotional support for

PLWHA [17]. Thus, family members were usually willing to help their own members in providing ancillary services addressing food, transportation and housing [18].

The additional financial costs incurred in providing care to someone with a chronic illness including HIV/AIDS could undoubtedly lead to negative economic consequences. Direct costs which arose from the expenditure on goods and services relating to care and indirect costs were associated with income forfeited by the care recipient or the caregiver through loss of employment or reduced productivity, causing financial strain on the caregiver [19]. Consequently, Turner and Catania [20] further explained that family caregivers with financial difficulties were exposed to greater life stress and burden than their counterparts for whom financial issue was not a problem.

Additionally, stigma and discrimination were the major social factors influencing care giving among HIV/AIDS family caregivers. Like family caregivers in other parts of the world [21-22], these caregivers also experienced HIV-related social stigma that manifested in various forms. In the present qualitative exploration, felt stigma [23] emerged as the most common stigma-related theme in families living with HIV/AIDS. This could be the cause for not disclosing their illness to the family members, friends and neighbours. Consequently, an atmosphere of caring in secrecy was established due to the fear of being discriminated. However, it was common for them to talk about opportunistic illnesses like TB or meningitis, to avoid rejection due to the stigma associated with HIV/AIDS. Additionally, enacted stigma [23] was experienced as an interpersonal discrimination. This seemed to stem from a fear of contagion and a lack of knowledge about HIV transmission. As such, the present findings are consistent with another investigation on public's fear and misconception about HIV transmission [24] which revealed that participants had incorrect beliefs about the possibility of viral transmission through casual contact with HIV patients.

Besides that, in this investigation, religion appeared to be a very important coping mechanism to deal with stigma as well as its related life stresses. Our findings also corroborated those of Mac Neil's [25] which cited that family caregivers could somehow

still describe caregiving as a comforting responsibility, and that they turned to religion as a source of strength to deal with the various caregiving demands. Another study suggested that spirituality and faith-based activities were important coping mechanisms for caregivers and PLWHA [26]. In our investigation, prayer was reported as a meaningful religious practice. According to the Qur'an and hadith, prayer, including contact prayer (salat), dua'a, zikr (dhikr) or remembrance of Allah and Qur'anic recitation brings a person closer to God [27] and was often prescribed as a treatment for various conditions and ailments. Furthermore, religion-based research demonstrated that praying had a positive effect on physical, psychological, and other types of well being [28]. In other studies, it has been shown that for the Christians, praying could also positively impact on important outcomes such as physical and mental health, and general well being [29].

Interestingly, several caregivers also attempted to seek spiritual approaches (based on indigenous belief systems) for patients in addition to modern approaches which are western-based therapies. The treatment given was considered more holistic as it targets the mind, body and soul of patients within their family, community and religious context [30]. In view of this, caregivers in this investigation were likely to attribute the origin of illness to "bad spirit" interference. Hence, *ustaz* (religious people) were usually consulted to identify and ward off the spirit [31]. Patients were given the "Holy" water (blessed with verses from the Holy Quran) for the healing of ailments. It was the Muslim belief that the words and recitation of Quran could overcome illness and distress as it was narrated in the teachings of Prophet Muhammad. Such treatment was considered effective when they felt energized and their mental state had recovered. Consistent with other studies in patients with HIV/AIDS, spirituality has also been associated with beneficial outcomes in HIV-positive individuals [32] such as less psychological distress [26], better cognitive and social functioning as well as fewer HIV symptoms [33].

It was also particularly noted that doctors and nurses were the key information resources for

family members. Thus, education and counselling to PLWHA's family members in clinical setting would be helpful to fulfill their needs [34]. The possible reason was that only several people had the ability to access and acquire information from the internet as most caregivers were the "older" generation who were less internet-literate. Furthermore, they were also fearful of public disclosure of the illness. Consequently, family members preferred direct consultation with doctors and nurses related to information about HIV/AIDS management, treatment side effects and care giving skills. Moreover, caregivers assumed their tasks for reasons that included a sense of familial obligation, loyalty and strengthening of the relationship with the HIV/AIDS patient. This was in line with other explorations that showed caring for a patient with advanced cancer has somehow been rewarding and these included satisfaction, closeness with the patient, and a sense of fulfilling an obligation [35]. The positive aspects of caregiving were also associated with psychological well being and the caregiver's willingness to continue providing care [36]. These could be further strengthened by psychological support and practical assistance with problem solving from health care professionals [37].

Limitations

This study has the following limitations. First, this investigation was based on a convenience sample; thus the overall findings may not truly represent the family caregivers in Terengganu. Second, the cross-sectional nature of the study has also limited the establishment of causal directions and restricted broader interpretation of the results.

Conclusion

In conclusion, this exploratory investigation managed to identify five main issues in HIV/AIDS caregiving- challenges of caregiving, financial issues, stigma and discrimination, support for caregivers and positive aspects of care giving. Lack of income, stigma and discrimination and insufficient support were the major challenges experienced by most respondents while religion served as the main coping resource to overcome caregiving-related stress. Thus,

multidisciplinary approaches utilising team-work combination of the medical specialists, psychiatrists, pharmacists and social workers could be formulated for effective strategies in addressing the identified issues.

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Corresponding author: *Pei Lin Lua, Professor of Pharmacy Practice, Centre for Clinical and Quality of Life Studies (CCQoLS), Faculty of Medicine and Health Sciences (FMHS), Universiti Sultan Zainal Abidin (UniSZA), Kampus Kota Jalan Sultan Mahmud, 20400 Kuala Terengganu, Malaysia.*

Email: peilinlua@unisza.edu.my

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