REVIEW ARTICLE

MENTAL HEALTH-RELATED EXPERIENCES AND CHALLENGES OF INFORMAL HIV/AIDS CAREGIVERS: A BRIEF REVIEW AND ANALYSIS

Pei Lin Lua & Norhayati Mustapha

Centre for Clinical and Quality of Life Studies (CCQoLS), Faculty of Medicine and Health Sciences (FMHS), Universiti Sultan Zainal Abidin (UniSZA), 20400, Kuala Terengganu, Terengganu, Malaysia.

Abstract

Objectives: **This paper mainly intended to review the experiences and challenges encountered particularly in mental health issues and to additionally analyze the methodologies used in studies involving HIV/AIDS informal caregivers.** ***Methods:*** **Four electronic databases; Science Direct, EBSCOhost, Ovid and Springer Link were searched for articles published in the past 10 years (2002 – 2012). Only full-text English articles related to research on care giving of HIV-infected adult patients were selected.** ***Results:*** **Twenty two out of 293 articles (7.5%) were reviewed, involving 2,765 caregivers in the USA (n=1,610), Africa (n=253), Asia (n=838) and Oceania (n=64) regions. A variety of age categories was involved in care giving with the youngest carer being 12 years old and the oldest, 60 years on average. Females and whites appeared to be dominant and 603 caregivers themselves were HIV-positive. The main outcomes measured were care giving burden, challenges and coping. Stress and depression, stigma and discrimination, insufficient support, role overload and extreme poverty were the main challenges experienced in care giving. Both qualitative (n=11) and quantitative (n=9) were the equally preferred types of study. Purposive sampling emerged as the most preferred sampling technique. Various instruments were utilized, but the Beck Depression Inventory (BDI) was the most popular particularly in quantitative studies.** ***Conclusion:*** **A variety of life aspects were negatively affected in the process of care giving for HIV/AIDS patients and studies of such nature commonly focused on caregivers' psychosocial burden.** ***ASEAN Journal of Psychiatry, Vol. 13 (2): July – December 2012: XX XX.***

Keywords: HIV/AIDS, Caregivers, Mental Health, Stress and Depression

Introduction

Acquired Immune Deficiency Syndrome (AIDS) has become one of the most devastating diseases the community has ever faced since it was first identified and recognized over 30 years ago. As of 2010, it has been estimated that approximately 34 million people were living with the human immunodeficiency virus (HIV), with an estimation of 1.8 million deaths from AIDS-related causes worldwide [1]. South Africa is reported to be the most severely affected region in the world while India has the largest population living with the disease in Asia. Among the developed countries, the United States of America has the highest prevalence, reported to be at 0.6% [1].

It is generally known that HIV/AIDS is not just a health issue because it clearly affects many

other aspects of life. Individuals infected with by HIV are commonly struggle with negative psychosocial impacts such as poverty, stigma, discrimination and depression which can ultimately affect their health-related quality of life (HRQoL), hence influencing health outcomes. Unfortunately, the prevalence of HIV/AIDS related stigma was reported to be higher among individuals who incorrectly believe that casual contact with a person who has HIV/AIDS can cause the disease [2]. Mental health is also a prominent psychosocial factor affecting patient's HRQoL. For example, depression in HIV-positive individuals tend to influence patient's adherence to antiretroviral therapy [3,4].

The diagnosis of a chronic illness and its accompanying treatment impacted significantly on the person diagnosed as well as their family who were generally affected in various ways including their emotional, physical and also psychological well-being [5,6]. Many studies have demonstrated that family caregivers of HIV-infected patients are constantly suffered from significant stress and were associated with care giving burden [7,8]. Additionally, another closely related issue is linked to stigmatization. A few studies have revealed that stigma and discrimination were the most prevalent factors causing stress due to disclosure of the disease [9].

In countries facing severe HIV/AIDS epidemics, the majority of those who were infected and affected by HIV were already living in poverty. Some were forced to sell their properties to cover the high economic burden of treatment and other costs associated to HIV/AIDS [10]. Worse still, poverty would pass onto the next generation when the parents died and the orphaned children were sent to relatives for subsequent care and upbringing. Consequently, further income loss could threaten the ability to meet basic living needs such as food, education and access to healthcare.

In view of the numerous problems plaguing these caregivers, this paper intends to review and analyse relevant published articles which have studied on care giving experiences and challenges in HIV/AIDS. The specific objectives are: 1) to investigate the experiences and challenges particularly in mental health issues and 2) to examine the research methodologies used in studies on HIV/AIDS care giving.

Methods

Search strategy and selection criteria

Four electronic databases; Science Direct, EBSCOhost, Ovid and Springer Link were searched for articles published in the past 10 years (2002 – 2012). Combination of the following keywords was utilized to retrieve the articles: HIV/AIDS, family caregiver, care giving, burden, impact and barriers. The keyword-based screening strategy was based on articles which met the inclusion criteria whereby only full-text English articles related to research on care giving of HIV-infected patients were selected. Excluded studies were those published in languages other than English, reviews and abstracts. Although care giving of HIV-infected children may also affect their parents' and caretakers' lives, our review only intended to focus on the informal caregivers of *adults* with HIV/AIDS.

Data collection and analysis

Demographic distribution for all participants in the selected studies was summarized according to the year, country, age, gender, ethnicity, religion, period of care giving, marital status and HIV status (Table 1). Additionally, the following information was dissected i.e. study design, sampling technique, sample size and recruitment, instruments, time taken (per interview), main care giving outcomes and major findings (Table 2). All information extracted from the articles were tabulated accordingly.

Table 1. An overview of demographic indicators of caregiver respondents involved in the reviewed studies (2002-2012)

No	• Year ➢ Author(s)	Country (place)	Age (mean / range / categories)	Gender (%)	Period of care giving (mean / range / categories)	Ethnicity / Religion (%)	Marital status (%)	HIV status (%)
1.	• 2003 ➢ Kespicha-yawattana and Van Landing-ham [11]	Thailand (Chiang Mai, Phichit and Rayong)	Mothers: Mean = 60.0 Fathers: Mean = 62.0	Male and female (not specified)	N/A	N/A	N/A	N/A
2.	• 2003 ➢ Land et al [12]	USA (Los Angeles and San Francisco)	HIV-positive: Mean = 36.9 HIV-negative: Mean = 39.2	Male = 100.0	HIV-positive = 1.8 years HIV-negative = 1.7 years	White = 78.0 Black = 8.0 Latino = 8.0 Other = 6.0	N/A	HIV-positive = 39.4 HIV-negative = 60.6
3.	• 2003 ➢ Mc Causland and Paken-ham [13]	Australia (Queensland)	Mean = 43.1 Range = 19.0 – 70.0	Male = 59.4 Female = 40.6	Mean = 39.1 months	Protestant = 10.9 Roman Catholic = 15.6 Other Christian = 15.6 Nil Religion = 17.3 Other Religion = 40.6	Unmarried = 53.1 Married = 21.9 Separated = 6.3 Divorced = 15.6 Widowed = 3.1	N/A
4.	• 2003 ➢ Wight et al [14]	USA (Los Angeles and San Francisco)	Mean = 39.2	Male = 100.0	1.9 years	Non-Hispanic White= 79.0 African American= 7.0 Hispanic= 8.0 Asian= 2.0 Other= 4.0	N/A	HIV-positive = 41.3 HIV-negative = 58.7
5.	• 2004 ➢ Chimwaza and Watkins [15]	Malawi (Balaka district)	N/A	Female = 100.0	N/A	N/A	Married= 40.0 Widowed= 13.3 Single= 46.7	N/A
6.	• 2004 ➢ Katapa [16]	Tanzania (Rungwe district)	Male: Range = 35.0 to 55.0 Female: Range = 23.0 to 78.0	Male = 7.0 Female = 93.0	N/A	N/A	Married= 55.0 Widowed= 35.0 Separated= 7.0 Divorced= 1.5 Single= 1.5	N/A
7.	• 2004 ➢ Pirraglia et al [17]	USA	Mean = 42.0	Male = 47.0 Female = 53.0	N/A	White= 40.9 African American= 27.3 Other= 31.8	Partnered/married= 43.2 Other= 56.8	HIV-positive = 44.3 HIV-negative = 55.7
8.	• 2004 ➢ Stetz and Brown [18]	USA	Mean = 39.0	Male = 20.0 Female = 80.0	N/A	Caucasian = 80.0 African American = 13.0 Other = 7.0	N/A	N/A

9.	• 2005 ➢ Moore and Henry [19]	Togo (Lome)	Mean = 60.0	Male = 14.0 Female = 86.0	10.2 months	Christian = 76.0 Muslim = 8.0 Indigenous = 12.0 Others = 4.0	Married = 30.0 Divorced = 8.0 Widowed = 34.0 Separated = 28.0	N/A
10.	• 2006 ➢ Demmer [20]	South Africa (KwaZulu-natal)	Mean = 35.0	Male = 22.2 Female = 77.8	N/A	Black = 90.0 Other = 10.0	N/A	N/A
11.	• 2006 ➢ Engler et al [21]	USA (Rhode Island)	Mean = 42.1	Male = 47.2 Female = 52.8	N/A	White= 40.9 Black= 27.3 Hispanic= 23.9 Other= 8.0	N/A	HIV-positive = 22.2 HIV-negative = 77.8
12.	• 2006 ➢ Mwinituo and Mill [22]	Ghana (Accra)	Range = 12.0 to 80.0	Male and female (not specified)	Mean = 2 years Range = 3 months to 5 years	N/A	Married= 54.5 Widowed= 9.1 Divorced= 9.1 Single= 27.3	N/A
13.	• 2006 ➢ Orner P. [23]	South Africa (Khayelitsha & Delft in the Western Cape)	Mean = 40.0	Male = 4.4 Female = 95.6	Categories: <2 years = 25% 2-5 years =37.5% > 5 years =37.5%	N/A	N/A	N/A
14.	• 2007 ➢ Kipp et al [24]	Uganda (Kibiito, Kahunge, Kaihura and Kataraka)	Range = 19.0 to 73.0	Male = 25.0 Female = 75.0	N/A	N/A	Married= 62.5 Widowed/ Divorced= 12.5 Single= 25.0	N/A
15.	• 2007 ➢ Miller et al [25]	USA	Mean = 41.2	Male = 47.0 Female = 53.0	N/A	White= 40.9 African American= 27.3 Other= 31.8	Partnered/Married= 43.2 Other= 56.8	HIV-positive = 44.3 HIV-negative = 55.7
16.	• 2007 ➢ Wight et al [26]	USA (Los Angeles)	Mean = 53.8	Female = 100.0	5.2 years	Non-Hispanic white= 17.0 African American= 27.4 Hispanic= 51.9 Other= 3.7	N/A	HIV-positive = 27.4 HIV-negative = 72.6
17.	• 2008 ➢ Bogart et al [27]	USA	Mean = 46.0 Range = 30.0-62.0	Male = 27.0 Female = 73.0	N/A	African American = 48.0 American Indian = 3.0 Latino = 21.0 White = 27.0	N/A	N/A
18.	• 2009 ➢ Aga et al [28]	Ethiopia (Addis Ababa)	Range = 16.0 to 76.0	Female = 100.0	N/A	Orthodox Christian= 77.8 Protestant Christian= 5.5 Muslim= 16.7	Married= 38.9 Widowed= 22.2 Divorced= 5.6 Single= 33.3	N/A

19.	• 2009 ➢ Feng et al [29]	Taiwan	Mean = 47.5	Male = 26.0 Female = 74.0	N/A	Buddhism= 44.0 Folk faith= 14.0 Christianity= 4.0 Taoism= 20.0 Other= 20.0 Nil= 2.0	Married= 64.0 Widowed= 12.0 Divorced= 6.0 Single= 14.0 Concubinage= 4.0	N/A
20.	• 2009 ➢ Mitchell and Knowlton [30]	USA (Baltimore, Maryland)	Categories: ≤45 years= 50.2% ≥45 years= 49.8%	Male = 42.5 Female = 57.5	N/A	Primarily African American	N/A	HIV-positive = 43.0 HIV-negative = 57.0
21.	• 2009 ➢ Pallangyo and Mayers [31]	Tanzania (Dar es Salaam)	Range = 33.0 to 50.0	Female = 100.0	N/A	N/A	Single= 37.5 Widowed= 25.0 Married= 37.5	HIV-positive = 50.0 HIV-negative = 50.0
22.	• 2009 ➢ Tshililo and Davhana-Maselesele [32]	South Africa (Limpopo province)	N/A	Male and female (not specified)	N/A	N/A	N/A	N/A

Table 2: Summary of studies on HIV/AIDS informal caregivers (2002 until 2012)

No	• Year ➢ Author(s)	• Study type ➢ Study design	Sampling technique	• Sample size (n) ➢ Recruitment sites / means	• Instrument(s) ➢ Administration	Time taken (per interview)	Main care giving outcome(s) examined	Major findings	Comments
1.	• 2003 ➢ Kespicha-yawattana and Van Landing-ham [11]	• Mixed-method (qualitative and quantitative ➢ N/A	Convenience sampling	• Quantitative (n = 770) • Qualitative (n = 18) ➢ Interme-diaries (local health officials)	• Center for Epidemiologic Studies-Depression Scale (CES-D) • Global Health Assessment (GHA) ➢ In-person interviews	N/A	Effects on health	• Anxiety • Insomnia • Fatigue • Muscle strain • Head and stomach aches	• Charac-teristics of respon-dents were not clearly described.
2.	• 2003 ➢ Land et al [12]	• Quantitative ➢ Cross-sectional	Purposive sampling	• n = 416 ➢ Community-based AIDS organiza-tions (32%) ➢ Media advertising (68%)	• Stress • Role overload • Role captivity • Financial strain • Self-esteem • Hopkins Symptom Checklist-90 (depression subscale)	Approximately 1.5 hours	Stress process and predictors of depressive symptoma-tology	• HIV-positive caregivers reported high levels of depress symptoma-tology than HIV-negative caregivers. • Poor health and financial concerns were specific predictors of	• Self-reported serostatus rather than testing for confirma-tion • Focused on sexual prefe-rence (gay and bisexual)

					➢ In-person interviews			depression. • HIV-negative specific predictor associated with care giving role.	
3.	• 2003 ➢ Mc Caus-land and Paken-ham [13]	• Quantitative ➢ N/A	Purposive sampling	• n = 64 ➢ Community-based AIDS organiza-tions ➢ Media advertising	• Caregiver health status • Caregiver social support • Caregiver coping strategies • Caregiver appraisal • Caregiver and care recipient global distress • Beck Depression Inventory (BDI) • The Caregiver Reaction Assessment (CRA) • The Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) • Care recipient health status ➢ In-person interviews	90 minutes	Benefits of care giving and relations among care giving adjustment, benefit finding, stress and coping variables	• Poorer care giving adjustment was positively correlated with care recipient distress and passive avoidant coping. • However, poorer adjustment was inversely correlated with social support and benefits.	• Assessing many variables could burden the caregivers (eight question-naires with 165 items)
4.	• 2003 ➢ Wight et al [14]	• Quantitative ➢ N/A	Convenience sampling	• n = 276 ➢ Community-based AIDS organiza-tions (32%) ➢ Mass media announce-ments (32%) ➢ Doctors' offices, clinics, health fairs, gay pride festivals and other miscella-neous sources (36%)	• Activities of daily life (ADL) • Duration of care giving • Role overload • Caregivers' perceptions of PLWHA symptoms • Financial worry • Social constriction • Emotional distress • Patients living with HIV/AIDS (PLWHA) family support ➢ In-person	Approximately two hours	Family support on AIDS caregivers' stress.	• Emotional distress among HIV-positive caregivers was associated with high care giving stress and low PLWHA family support. • Financial worry exacerbated the impact of role overload.	• Focused on sexual preference (gay) • Assessing many variables could burden the caregivers (five question-naires with 74 items)

					interviews				
5.	• 2004 ➢ Chimwaza and Watkins [15]	• Qualitative ➢ N/A	N/A	• n = 15	• None ➢ In-person interviews	Approximately one hour	Care giving experience	• Reluctance to acknow-ledge disease as AIDS • Financial burden • Physically and emotionally demanding	• Only females managed to be recruited thus, generaliza bility to other gender was limited.
6.	• 2004 ➢ Katapa [16]	• Qualitative ➢ N/A	N/A	• n = 60 ➢ N/A	• None ➢ In-person interviews ➢ Focus group discussion with 30 caregivers in each community.	N/A	Care giving experience	• Lack of household basic needs for the patients • Assets were sold in order to buy medicine for the patients. • Most worked under stress and received no support from the community (resulting in stigma to family members).	• Different groups of caregiver were involved in in-depth interviews and focus group discussion hence extensive expe-rience of care giving could be obtained.
7.	• 2004 ➢ Pirraglia et al [17]	• Quantitative ➢ Cross-sectional	N/A	• n = 176 (dyads) ➢ Brown University AIDS Programme	• Beck Depression Inventory (BDI) • Caregiver Strain Index (CSI) ➢ In-person interviews	N/A	Relation-ship between depression and caregiver burden	High caregiver burden was strongly associated with depression	• HIV patients were also involved, hence asso-ciation between caregivers' depression and well-being of HIV patient could be assessed.
8.	• 2004 ➢ Stetz and Brown [18]	• Quantitative ➢ N/A	Convenience sampling	• n = 15 ➢ Community-based AIDS agencies ➢ Mass media announce-ments ➢ Home health care agencies	• Center for Epidemiologic Studies-Depression Scale (CES-D) • Bereavement Item Scale • The Symptoms of Stress Scale (SOS) • Caregiver Reaction Assessment • Caregiving	N/A	Physical and emotional health	• High level of stress and depression • Health problems limited ability to socialize	• Age of AIDS caregivers were younger than cancer caregivers, hence compare-sons were limited by variability in sample characteris tics.

					Demands Scale • The Interpersonal Relationship Inventory (IPRI) • The Mutuality Scale • The Support Behaviors Inventory • The Short Form Health Survey • The Quality of Life Scale ➢ In-person interviews				
9.	• 2005 ➢ Moore and Henry [19]	• Mixed method (qualitative and quantitative) ➢ N/A	N/A	• n = 50 ➢ Non-governmental organizations	• Demands • Workload • Family stress • Support ➢ In-person interviews	Average of one hour	Care giving experience	Challenges identified:- • Not prepared for the demanding role of care giving. • Financial burden, frustration, despair and isolation • Depletion of resources	• Focused on older caregivers, thus findings could not be generalized to young caregivers.
10.	• 2006 ➢ Demmer [20]	• Qualitative ➢ N/A	Purposive sampling	• n = 18 (caregivers who had lost loved ones to AIDS) ➢ N/A	• None ➢ In-person interviews	N/A	Care giving experience	• Stigma and denial • Lack of support	• Past experience of care giving
11.	• 2006 ➢ Engler et al [21]	• Quantitative ➢ Cross-sectional	N/A	• n = 176 ➢ Brown University Medical Clinics.	• Caregiver Strain Index (CSI) • HIV coping scale • Beck Depression Inventory (BDI) • Symptom Factor-36 Scale • Caregivers' perceptions of PLWHA symptoms ➢ In-person interviews	90 minutes	Role of coping on caregiver burden	• Coping types which significantly and positively correlated with caregiver burden:- • blame-withdrawal • active-approach • distancing • Caregiver burden significantly and positively associated with stress	• Assessing many variables could burden the caregivers (five questionnaires with 62 items)

								and caring patients with poor physical functioning and low CD4 count (<200).	
12.	• 2006 ➢ Mwinituo and Mill [22]	• Qualitative ➢ N/A	Purposive sampling	• n = 11 ➢ HIV outpatient clinic	• None ➢ In-person interviews	Up to 4 hours (due to interruption by visitor)	Care giving experience	• Loss of jobs due to discrimination • Stigma in relation to:- ➢ Provision of care in secrecy ➢ Loneliness and isolation ➢ Lack of support ➢ Disrespect from health workers	• Long duration of interview could burden the caregivers
13.	• 2006 ➢ Orner P. [23]	• Qualitative ➢ N/A	Purposive and snowball sampling	• n = 45 ➢ N/A	• None ➢ In-person interviews	N/A	Psycho-social impacts on caregivers and care giving experience	Impacts of care giving:- • Insufficient support • Poverty • Lack of basic resources • Stigma and prejudice	• Two sampling techniques were employed • Thus, large respon-dents were recruited
14.	• 2007 ➢ Kipp et al [24]	• Qualitative ➢ N/A	N/A	• n = 16 ➢ Home-based care program.	• None ➢ In-person interviews	N/A	Caregiver burden and coping strategies	• Role of male family members • High burden • Coping mechanism • Lack of knowledge and skills in care provision • Lack of support	• The recruitment was gender-specific (female) • Generalizability to other cohort of caregivers was limited
15.	• 2007 ➢ Miller et al [25]	• Quantitative ➢ Cross-sectional	N/A	• n = 176 (dyads) ➢ Brown University AIDS Programme	• Family Assessment Device (FAD) • Characteristics of patient/care-giver relationship • Social support	N/A	Relation-ship quality of HIV patients-caregivers	Relationship is associated with:- • Depression and burden • Patients' depression • Physical	• Assessing many variables could burden the caregivers (seven question-naires with

					• Beck Depression Inventory (BDI-I) • Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) • Caregiver Strain Index • HIV treatment adherence ➢ In-person interviews			impairment • HIV medication adherence	103 items)
16.	• 2007 ➢ Wight et al [26]	• Quantitative ➢ N/A	Convenience sampling	• n = 135 (dyads) ➢ AIDS organization mailings (46.7%) ➢ Service provider referral (18.2%) ➢ Posted flyers (16.2%) ➢ Word-of-mouth (6.8%) ➢ Unspecified means (12.1%).	• Impacts of Events Scale (IES) • Stress variables • Activities of daily living (ADL) • Role overload • Dyadic adjustment • Perceived AIDS stigma • Constriction of social activities • Financial worry • Emotional distress ➢ A structured computerized interviews	Approxi-mately two hours.	HIV-related traumatic stress symptoms	High level of traumatic stress was associated with:- • Being HIV positive • Feeling overloaded by care giving demands • High levels of HIV stigma.	• Assessing many variables could burden the caregivers (eight question-naires with 120 items) • Incentive was provided
17.	• 2008 ➢ Bogart et al [27]	• Qualitative ➢ N/A	N/A	• n = 33 ➢ HIV Cost and Services Utilization Study (HCSUS)	• None ➢ In-person interviews	Approximately 1.5 hours	Interconnec tedness of stigma experiences	• Different types of stigma (felt stigma and enacted stigma) experienced. • Fears due to prejudice and discrimina-tion were reported.	• Parents, children and caregivers involved interviews hence extensive expe-rience of care giving could be obtained.
18.	• 2009 ➢ Aga et al	• Qualitative-focused	Purposive sampling	• n = 18 (6 key	• None	45 to 60 minutes	Influence of socio-	Influential sociocultural	• Charac-teristics of

	[28]	ethnography ➢ N/A		participants & 12 general participants) ➢ N/A	➢ In-person interviews aided by participant observation		cultural factors in care giving	factors:- • Religious beliefs • Economic issues • Education • Social stigma and discrimination	key participants and general participants were not clearly described. • The recruitment was not gender specific hence, only females managed to be recruited

19.	• 2009
	➢ Feng et al [29]
		• Quantitative
		➢ Cross-sectional
			N/A	• n = 50
				➢ Medical centre
					• Family Stress Scale
					• Family Needs Scale
					• Sources of Family Needs
					• Quality of Life (QoL) Assessment
					➢ In-person interviews
						N/A	Stress, needs and quality of life (QoL)	• Disclosure and stigma
								• Patients' interpersonal relationship.
								• Care-related needs:
								  • Knowledge of disease progression
								  • methods of examination
								  • treatment and the related side effects
								• Stress was significantly and positively correlated with needs and negatively correlated with QoL
								• Interpersonal relationship with PLWHA improved (after knowing about HIV infection
									• Assessing many variables could burden the caregivers (four questionnaires with 99 items)

								and caring for PLWHA)	
20.	• 2009 ➢ Mitchell and Knowlton [30]	• Quantitative ➢ Cross-sectional	N/A	• n = 207 ➢ N/A	• Community Epidemiology Study-Depression (CES-D) • Stigma Scale • Disclosure Scale • Physical functioning • Caregiver burden ➢ In-person interviews using a computer-assisted personal interviewing approach (CAPI)	Approximately 1 hour and 15 minutes	Stigma, disclosure and depressive symptoms among informal caregivers	• Stigma was associated with more depressive symptoms • Significant decrease in depressive symptoms with increasing number of disclosure	• This study was conducted in areas with high preva-lence of drug use thus, generaliza bility limited to urban African American.
21.	• 2009 ➢ Pallangyo and Mayers [31]	• Qualitative, descriptive and exploratory (based on interpretive paradigm) ➢ N/A	Purposive sampling	• n = 8 ➢ Pastoral Activities and Services for People with AIDS (PASADA)	• None ➢ In-person interviews	Approximately 45 to 60 minutes	Care giving experience	• Financial constraints impacted upon the costs of caring. • Stigma and discrimi-nation • Stress (patient-related, emotional and physical exhaustion) • Care burden and challenges (multiple roles, caregiver's health, lack of education and unemployme nt) • Limited support	• The recruitmen t was gender specific (female) • Generaliza bility to other cohort of caregivers was limited
22.	• 2009 ➢ Tshililo and Davhana-Masele-sele [32]	• Qualitative, phenome-nological, explorative, descriptive and contextual	Purposive sampling	• n = 12 ➢ N/A	• None ➢ In-person interviews	N/A	Care giving experience	Experience of negative feelings (in extreme poverty) • Sadness • Pain	• Demo-graphic distribu-tions were not clearly explained, making study generaliza

		➢ N/A						• Anger • Depression • Frustration	bility to those with different demo-graphic charac-teristics difficult.

Results

From the year 2002 until 2012, a total of 22 studies involving care giving HIV/AIDS were found. Among these, eight were published in AIDS Care, two were published in AIDS and Behavior and the rest were traced from various journals such as the International Journal of STD & AIDS, AIDS Patient Care and STDs, Journal of the Association of Nurses in AIDS Care, Ageing International, Journal of General Internal Medicine, Journal of Loss and Trauma, Psychosomatic Medicine, Nursing and Health Sciences, Health Care for Women International, Public Health Nursing, Journal of Nursing Scholarship and Western Journal of Nursing Research (one article each).

Most of the published articles were originated from studies conducted in the African continent (n=10) and the United States of America (n=9). The former were carried out particularly in South Africa (n=3), Tanzania (n=2), Malawi (n=2), Ghana (n=1), Uganda (n=1), Ethiopia (n=1), and Togo (n=1). On the other hand, only three trials were carried out in the Asian and Oceanian regions involving Taiwan, Thailand and Australia.

Demographic characteristics of HIV/AIDS informal caregivers

The total number of participants enrolled in all the included trials from the year 2002 until 2012 is 2,765. The majority of informal caregivers included in this review ranged from 18-50 years old. Only one study focused on older informal caregivers (mean age = 60 years) [17] while two studies reported that the youngest carer was as young as 12 years old [14,21].

In studies not focusing on any specific gender of informal caregivers, females appeared to be the predominant gender, whereby its percentage was higher (range = 40.6% to 95.6%) compared to males (range = 4.4% to 47.2%). The two trials focusing on female as informal caregivers were carried out in United States of America and Tanzania. Interestingly, the two studies conducted in Los Angeles and San Francisco, USA had involved male (gay and bisexual) informal caregivers. Nevertheless, distribution of the caregivers' gender was not documented in three reviewed articles [21,31]. Based on the caregivers' ethnicity in our findings, they were largely represented by the main ethnic group, dominated by whites in studies that were carried out in USA although the majority of PLWHA in the USA were primarily African Americans [33]. Nonetheless, ethnicity was not specifically reported in three out of the 22 trials which merely stated that most of the respondents were Christians. Besides, seven studies neither reported the ethnicity nor religion of the respondents. On the other hand, marital status of informal caregivers was only reported in ten studies of which majority were already married (21.9% - 64.0%).

Additionally, only eight studies including information on the HIV status of the corresponding informal caregivers whereby HIV-negative caregivers (77.8%) have clearly outnumbered their HIV-positive counterparts (50.0%). The period of care giving was mentioned in six studies whereby many have become carers for more than 12 months. Only one study reported that the average duration of care giving was less than 12 months.

Definition of caregivers

Many of the reviewed articles did not provide a clear definition for "caregiver". Only one study clearly stated the definition and the characteristics of a caregiver, in which defined

as "primary caregivers who provide ongoing practical assistance with activities of daily living to a friend, partner, or family member" [12]. Informal caregivers in this study were those providing unpaid care, thus excluding trained volunteers or paid home professionals. Nonetheless, some studies only stated their required characteristics of caregivers as part of the inclusion criteria whereas one study did not include caregivers who were blood relatives of the patients.

Care giving experiences and challenges

Eight out of the 22 articles (36.4%) focused mainly on the care giving experiences as well as the challenges faced by informal caregivers. Financial burden and worries were highlighted in eight articles and care giving was reported to be influenced by role overload. This seemed to impose burden on caregivers and could be worsen by the additional responsibilities of caring for household matters.

Issues related to stress and depression were elaborated by thirteen articles (61.9%). Seropositive caregivers reported the significantly higher levels of stress due to financial concerns and low self-esteem traits as they were younger, less educated, earned less income and were less likely to be employed [12,14]. Additionally, stress was significantly associated with feeling overloaded by care giving demands [26] especially with regard to caring for PLWHA with a CD4 count of less than 200 and having poorer physical functioning [21]. In addition, stigma significantly exacerbated the stress levels of caregivers [23,26,29]. Together, stigma and discrimination were linked to the incidence of fear and anxiety among other family members [32]. Besides that, the level of stress was also significantly and positively correlated with needs i.e. knowledge of the disease progression, methods of examination, treatment and the related side effects [29].

Pirraglia et al [17] further reported that the burden of care giving, medical comorbidities (other than HIV), illicit drug uses, other caring responsibilities (other than HIV patients), spending all day together and the duration of HIV diagnosis were strongly associated with depression. Moreover, a qualitative study showed that emotional demands impacted negatively on caregivers' mental health. Poverty, poor infrastructure, lack of affordable public transport and difficulties in accessing care were all contributory to their stress [30]. In cases of extreme poverty, other family members similarly experienced negative feelings characterized by sadness, pain, anger, depression and frustration [32].

In another qualitative study conducted by Pallangyo and Mayers [31], long term caring, stigma and discrimination and dealing with unresolved and recurring problems have led to a sense of helplessness, tearfulness, somatisation and discouragement. It was also reported that due to their role as caregivers, some respondents have even withdrawn from the society's circle, thus resulting in loneliness and isolation [18,22]. In a study conducted in Thailand, more than half of all AIDS-affected household fathers and mothers experienced anxiety and insomnia during the time of caring for their child with AIDS and this percentage has risen to beyond 70% for mothers and fathers who were primary caregivers [11].

Family support and relationship quality between caregiver and patient were further discussed in two articles. Apart from that, lack of support from extended families, the government and NGOs was reported to worsen current distressing problems in six studies. Besides that, only one article focused on the role of coping with care giving burden. Blame-withdrawal, active approach and distancing were the three types of coping strategies which were significantly and positively correlated with care giving burden [20].

Methodology of studies

Only from seven studies the information regarding methodological issues managed to be extracted. Based on the types of study, both qualitative (n=11) and quantitative (n=9) were

the equally preferred types while mixed-method (quantitative and qualitative) was only employed in two trials. In-person interviews with broad, open-ended questions and additional probe were utilized in order to draw further information about the issues in most qualitative studies. In contrast, structured questionnaires administered through trained personal interviewers were employed as the main data collection method in quantitative studies. Additionally, structured questionnaires were used in combination with interviews with the key informants in mixed-method (n=2).

The sample size of respondents varied widely in each study, ranging from 8 to 770. Most of the qualitative studies had included relatively small samples (8 to 45 respondents) while the quantitative studies enrolled over 100 respondents each, with the highest number being 770. Only one quantitative study consisted of only 50 respondents. None of the studies reviewed was carried out as randomized controlled trials (RCT). Nevertheless, six studies employed a cross-sectional design while purposive sampling emerged as the most preferred sampling technique. A variety of respondent recruitment methods have also been employed. Firstly, respondents were enrolled with the help of non-governmental organizations (NGOs) while a second approach utilized the mass media advertisements. The third method gathered respondents with the cooperation of healthcare institutions, although some trials used a combination of the methods mentioned earlier.

Various kinds of instrument were used in the quantitative studies. Questionnaires assessing depression was found to be the most popular, whereby the Beck Depression Inventory (BDI) and the Caregiver Strain Index (CSI) appeared as the most frequently utilized instruments for the respective study purposes.

Additionally, the time taken for interviews was also reported in eleven studies which took between 45 minutes to two hours. Unfortunately, due to the interruption from visitors, one study reported that the time taken for a session was nearly four hours.

Discussion

This brief review intended to provide a structured analysis of published articles over the past 10 years in the area of care giving for HIV/AIDS sufferers. Among others, the experiences and challenges of care giving, methodological issues, suggestions for future investigations as well as the limitations involved are importantly highlighted.

According to the overall assessment, more than 90% of the studies were carried out in the African continent and the United States of America. This clearly demonstrated that studies of such nature are still inadequate in the European and Asian countries although it was estimated that in 2010, 2.3 million and 4.3 million people were living with HIV in the respective continents [1]. In addition, although the national HIV prevalence in most Asian countries is relatively low (e.g. India = 0.3%), the population density of some countries is so vast that these low percentages had actually represent a very large numbers of people with HIV infection. Hence, more research on care giving should be conducted in this less-studied region to examine geographical, cultural and social differences which may affect care giving outcomes in various cohort of patients.

Irrespective of any specific gender, female caregivers were reported to spend more time on care giving responsibilities than their male counterparts in this review. This nurturing and caring role was traditionally and culturally regarded as women's responsibilities for their spouses and children [34]. Not surprisingly, studies on family care giving have also generally been focused on female family caregivers in other HIV/AIDS-related studies [9,35].
A variety of age categories was involved in our analysed studies. Young caregivers were usually reported to be responsible for domestic work (e.g. cooking, fetching water and wood) because they live in the same house with the sick parents or siblings [36]. Unfortunately, due to the impact of caring responsibilities, their school attendance became irregular or they could even completely dropout in the end [37]. On the other hand, older

caregivers were reported feeling overwhelmed by the magnitude and multiplicity of tasks they had to perform [38]. This demanding task was reported to negatively affect them in various life aspects such as economic, emotional, physical, and nutritional issues, which impacted upon their health and well-being [39]. As a result, caregivers' role in these two differing cohorts should be acknowledged and constantly supported considering that they were very much lacking in basic care giving education coupled with inadequate resources in home care [38].

The current studies in our review appeared to look specifically at the negative mental outcomes of HIV/AIDS care giving such as stress and depression with very little emphasis on the positive outcomes of PLWHA care giving. This was in concordance with other reviewed studies in mental illness and HIV/AIDS which also examined negative outcomes [5,40]. Thus, future studies are needed to explore both the negative as well as the positive aspects of care giving for PLWHAs.

A huge proportion of caregivers of PLWHA was clearly affected by symptoms of depression. The analysed studies showed that care giving burden was strongly associated with depression in particular [17,21,25]. This was not unexpected as depression was also highly prevalent among family caregivers of other chronic diseases such as cancer and schizophrenia. For example, it was reported that care giving burden was positively linked to depressive symptoms in Chinese caregivers of cancer patients [41] while caregivers of schizophrenia patients were also reported of worse emotional functioning in comparison to other aspects [42]. Thus, healthcare personnel in contact with caregivers should consider screening these individuals too for possible mental disorders and attempt to recommend further evaluation by the physicians if necessary.

It was particularly noted that seropositive women caregivers experienced greater burden of care giving-related stress which could be due to them being the more likely primary household providers who also cared for their children [43]. On top of that, these women were confronted with the challenge of being both a patient as well as a family caregiver in the course of their illness. In the United States, a study conducted qualitatively exploring this dual-challenge showed that all women exhibited evidence of clinical depression [44]. However, in caregivers who were self-identified as gay, depression is a function of social constriction and AIDS-related bereavement [45]. This meant that they usually isolate themselves from their extended family and communities to protect themselves as well as their care recipient from maltreatment. Consequently, some caregivers reported that they did not receive any valuable supports from their family members as well as from the community [46].

In addition to problems with depression, the most prevalent factor causing stress among caregivers were stigma and discrimination due to disclosure of the disease [47]. Caregivers were reported loss of jobs and employment opportunities as well as lack of respect from health workers because of these issues [48]. As a result, the care giving process was carried out in absolute secrecy [49]. Race also played an important role in HIV-related stigma. In a study conducted in South Africa, blacks were more likely to report experiencing stigma in their families compared to non-blacks counterparts [50]. Physical stigma (isolation from family members), social stigma and verbal stigma were the types of secondary stigma commonly experienced by the caregivers [51]. Additionally, living in excruciating economic burden might have also imposed a tremendous psychological pressure due to societal discrimination and isolation [52]. Attempts should hence be made by the relevant authorities to minimise these misfortunes in families with HIV/AIDS problems.

In the context of rapid demographic and socioeconomic change, the impact of care giving for rural and urban caregivers may also be different. In these analysed articles, depression and caregiver's burden were the main issues addressed in urban areas such as San Francisco and Los Angeles which further identified role overload and employment status as the strongest

predictor of depression in HIV-seropositive male partners [45]. In contrast, poverty, stigma and discrimination were the main problems faced by caregivers in sub Saharan Africa which were significant among caregivers in the rural areas [53]. This trend might be due to the limited access to outreach programmes and community health services [54]. Therefore, better understanding of rural-urban differences in care giving outcomes could be beneficial in designing supportive services for informal caregivers.

Despite the challenges and negative experiences reported by informal caregivers, none of the trials provided interventions aimed at reducing their psychosocial burden. Educational interventions that aimed at reducing stigmatization are hence valuable and should be disseminated. Essentially, the programme needs to provide accurate knowledge and correct the inaccurate beliefs towards HIV/AIDS on a continuous basis [55]. A study conducted among children living in communities with high HIV prevalence in rural China has proven that children with better AIDS knowledge possessed less personal stigma towards PLWHA [56]. This encouragingly showed that sound knowledge of HIV maybe influential in changing the people's behaviour and attitudes towards this fatal and infectious disease.

Throughout the investigations, both qualitative and quantitative approaches were widely employed in exploring care giving experiences and challenges, despite the mixed method representing the more comprehensive technique in HIV/AIDS research. The latter served a dual purpose of gaining focused, measurable and comparative data from larger samples as well as obtaining more in-depth information of the related issues from smaller cohorts such as commonly seen in this type of research [57]. Thus, it is reasonable that the mixed method approach should be more frequently adopted in future investigations, in order to enhance understanding of care giving in HIV/AIDS research.

Selection bias also appeared to be very common across all the reviewed studies. Most respondents were self-enrolled through numerous channels (e.g., community services, media announcements, gay festivals), hence possibly leading to over-representation of a particular group of informal caregivers, such as gay male partners and older caregivers. Additionally, there were also studies which focused on a specific gender, whereby as a result of this, the generalizability of the outcomes became rather limited.

Limitations

There are inevitably several drawbacks in this review. Our limited access to online databases which stored predominantly English-language literature, may have indirectly neglected the non-English articles. The latter may importantly contain information which could complement the existing research findings. Besides, this review only covered articles from four electronic databases namely Science Direct, EBSCOhost, Ovid and Springer Link, hence limiting the scope of search, let alone the limitation using the manual method. As highlighted earlier, since the majority of trials have been conducted in Africa and the USA, our findings may not be generalizable to HIV caregivers in other regions. Consequently, additional investigations should be initiated within more diversified groups of respondents for a more comprehensive coverage.

Conclusion

In conclusion, majority of the studies were carried out in the African region and the United States of America with a wide range of age categories was reported to be involved in care giving. In studies not focusing on a specific gender, females appeared to be dominant. Stress and depression, stigma and discrimination, insufficient support, role overload and extreme poverty were the main challenges reported. Therefore, the integration of medical, psychological and social services by both primary clinicians and community-based outreach staff would be beneficial for caregivers.

At its most expansive, multidisciplinary cooperation from psychologist, psychiatrist, social worker, medical specialist and pharmacist are deemed necessary and effective in addressing the above issues. Both qualitative and quantitative were the equally preferred types of study while numerous life aspects were negatively affected by care giving for HIV/AIDS patients. Consequently, future research should not only investigate the impact of care giving in other regions but also attempt to develop and test effective interventions (e.g. educational programme, support group) which could assist in improving the caregivers' HRQoL in order to provide optimal quality in care giving.

References

1. 2011 UNAIDS World AIDS Day Report. Joint United Nations Programme on HIV/AIDS. Available at: http://www.un.org/en/events/aidsday/2011/report.shtml. Accessed on February, 15 2012.

2. Qian HZ, Wang N, Dong S, Chen H, Zhang Y, Chamot E, et al. Association of misconceptions about HIV transmission and discriminatory attitudes in rural China. AIDS Care. 2007;19(10):1283-7.

3. Barbara AN. Quality of life in the HIV-positive patient: implications and consequences. J Assoc Nurses AIDS Care. 2004;15(5):20-7.

4. Shin SM, Espiritu M, Zeladita J, Sanchez E, Callacna M, Rojas C, et al. Psychosocial impact of poverty on antiretroviral nonadherence among HIV-TB coinfected patients in Lima, Peru. J Int Assoc Physicians AIDS Care. 2008;7(2):74-81.

5. Prachakul W, Grant JS. Informal caregivers of persons with HIV/AIDS: a review and analysis. J Assoc Nurses AIDS Care. 2003;14(3):55-71.

6. Wacharasin C, Homchampa P. Uncovering a family caregiving model: Insights from research to benefit HIV-infected patients, their caregivers and health professionals. J Assoc Nurses AIDS Care. 2008;19(5):385-96.

7. Abasiubong F, Bassey EA, Ogunsemi OO, Udobang JA. Assessing the psychological well-being of caregivers of people living with HIV/AIDS in Niger Delta region, Nigeria. AIDS Care. 2011;23(4):494-500.

8. Lee SJ, Li L, Jiraphongsa C, Rotheram-Borus MJ. Caregiver burden of family members of persons living with HIV in Thailand. Int J Nurs Prac. 2010;16:57-63.

9. Hejoaka F. Care and secrecy: being a mother of children living with HIV in Burkina Faso. Soc Sci Med. 2009;69(6):869-76.

10. Muniyandi M, Ramachandran R, Balasubramanian R. An economic commentary on the occurrence and control of HIV/AIDS in developing countries: Special reference to India. Expert Opin Pharmacother. 2006;7(18):2447-54.

11. Kespichayawattana J, Van Landingham M. Effects of coresidence and caregiving on health of Thai parents of adult children with AIDS. J Nurs Scholarsh. 2003;35(3):217-24.

12. Land H, Hudson SM, Stiefel B. Stress and depression among HIV-positive and HIV-negative gay and bisexual AIDS caregivers. AIDS Behav. 2003;7(1):41-53.

13. Mc Causland J, Pakenham KI. Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding and stress and coping variables.

AIDS Care. 2003;15(6):853-69.

14. Wight RG, Aneshensel CS, LeBlanc AJ. Stress buffering effects of family support in AIDS care giving. AIDS Care. 2003;15(5):595-613.

15. Chimwaza AF, Watkins SC. Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. AIDS Care. 2004;16(7):795-807.

16. Katapa RS. Caretakers of AIDS patients in rural Tanzania. Int J STD AIDS. 2004;15:673-78.

17. Pirraglia PA, Bishop D, Herman DS, Trisvan E, Lopez RA, Torgersen CS, et al. Caregiver burden and depression among informal caregivers of HIV-infected individuals. J Gen Intern Med. 2005;20:510-14.

18. Stetz KM, Brown M. Physical and psychosocial health in family caregiving: a comparison of AIDS and cancer caregivers. Pub Health Nurs. 2004;21(6):533-40.

19. Moore AR, Henry D. Experiences of older informal caregivers to people with HIV/AIDS in Lome, Togo. Ageing Int. 2005;30(2):147-66.

20. Demmer C. Caring for a loved one with AIDS: a South African perspective. J Loss Trauma. 2006;11:439-55.

21. Engler P, Anderson B, Herman D, Bishop D, Miller I, Pirraglia P, et al. Coping and burden among informal HIV caregivers. Psychosom Med. 2006;68:985-92.

22. Mwinituo PP, Mill JE. Stigma associated with Ghanaian caregivers of AIDS patients. West J Nurs Res. 2006;28(4):369-82.

23. Orner P. Psychosocial impacts on caregivers of people living with AIDS. AIDS Care. 2006;18(3):236-40.

24. Kipp W, Tindyebwa D, Rubaale T, Karamagi E, Bajenja E. Family caregivers in rural Uganda: the hidden reality. Health Care Women Int. 2007;28:856-71.

25. Miller IW, Bishop DS, Herman DS, Stein MD. Relationship quality among HIV patients and their caregivers. AIDS Care. 2007;19(2):203-11.

26. Wight RG, Beals KP, Miller-Martinez D, Murphy DA, Aneshensel CS. HIV-related traumatic stress symptoms in AIDS caregiving family dyads. AIDS Care. 2007;19(7): 901-9.

27. Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, et al. HIV-related stigma among people with HIV and their families: a qualitative analysis. AIDS Behav. 2008;12:244-54.

28. Aga F, Kylmä J, Nikkonen M. Sociocultural factors influencing HIV/AIDS care giving in Addis Ababa, Ethiopia. Nurs Health Sci. 2009;11:244-51.

29. Feng MC, Feng JY, Chen TC, Lu PL, Ko NY, Chen YH. Stress, needs and quality of life of family members caring for adults living with HIV/AIDS in Taiwan. AIDS Care. 2009;21(4):482-89.

30. Mitchell MM, Knowlton A. Stigma, disclosure and depressive symptoms among informal caregivers of people living with HIV/AIDS. AIDS Patient Care STDS. 2009;23(8): 611-17.

31. Pallangyo E, Mayers P. Experiences of informal female caregivers providing care for people living with HIV in Dar es Salam, Tanzania. J Assoc Nurses AIDS Care. 2009;20(6):481-93.

32. Tshililo AR, Davhana-Maselesele M. Family experiences of home caring for patients with HIV/AIDS in rural Limpopo Province, South Africa. Nurs Health Sci. 2009;11:135-43.

33. Centers for Disease Control and Prevention. HIV Surveillance Report, 2010; vol. 22.http://www.cdc.gov/hiv/topics/surveillance/resources/reports/. Published March 2012. Accessed March 13, 2012.

34. Huang C. Informal female caregivers of older adults with dementia in Taiwan. Californian J Health Promot. 2004;2(3):53-66.

35. Kipp W, Nkosi TM, Laing L, Jhangri GS. Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. AIDS Care. 2006;18(7):694-97.

36. Robson E, Ansell N, Huber US, Gould WTS Van Blerk L. Young caregivers in the context of the HIV/AIDS pandemic in sub-Saharan Africa. Population, Space Place. 2006; 12(2):93-111.

37. Becker S. Global perspectives on children's unpaid care giving in the family. Global Soc Policy. 2007;7(1):23-50.

38. Lindsey E, Hirschfeld M, Tlou S. Home-based care in Botswana: experiences of older women and young girls. Health Care Women Int. 2003;24(6):486-501.

39. Ssengonzi R. The plight of older persons as caregivers to people infected/affected by HIV/AIDS: Evidence from Uganda. J Cross Cult Gerontol. 2007:22:339-53.

40. Hsiao CY, Riper MV. Research on care giving in Chinese families living with mental illness: A critical review. J Fam Nurs. 2010;16(1):68-100.

41. Young SR, Young HY, Park S, Shin DO, Lee KM, Han JY, et al. Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. J Clin Oncol. 2008;26(36):5890-95.

42. Lua PL, Abu Bakar Z. Health-related quality of life profiles among family caregivers of patients with schizophrenia. Fam Comm Health. 2011;34(4):331-9.

43. Parrish M, Burry C, Pabst MS. Providing comprehensive case management services to urban women with HIV/AIDS and their families. Affilia. 2003;18:302-15.

44. Hackl KL, Somlai AM, Kelly JA, Kalichman SC. Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. Health Soc Work. 1997;22(1):53-62.

45. Wight RG. Precursive depression among HIV infected AIDS caregivers over time. Soc Sci Med. 2000;51:759-70.

46. Hlabyago KE, Ogunbanjo GA. The experiences of family caregivers concerning their care of HIV/AIDS orphans. SA Fam Pract. 2009;51(6):506-11.

47. Clark HJ, Lindner G, Armistead L, Austin B. Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. Women Health. 2003;38(4):57-71.

48. Santiesteban Y, Castro M, Calvo M. Mental health of primary caregivers for children and adolescents with HIV/AIDS in Cuba. MEDICC Rev. 2012;14(2):30-4.

49. Spirig R. HIV/AIDS family care-giving in Switzerland in the context of silence. Pflege. 2001;14(6):377-85.

50. Brown DC, BeLue R, Airhihenbuwa CO. HIV and AIDS-related stigma in the context of family support and race in South Africa. Ethn Health. 2010;15(5):441-58.

51. Ogunmefun C, Gilbert L, Schatz E. Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. J Cross Cult Gerontol. 2011;26:85-102.

52. Ji G, Li L, Lin C, Sun S. The impact of HIV/AIDS on families and children- a study in China. AIDS. 2007;21(8):157-61.

53. Wong LP, Syuhada AR. Stigmatization and discrimination towards people living with or affected by HIV/AIDS by the general public in Malaysia. Southeast Asian J Trop Med Public Health. 2011;42(5):1119-29.

54. Bedard M, Koivurania A, Stuckey A. Health impact on caregivers of providing informal care to a cognitively impaired older adult: rural versus urban settings. Can J Rural Med. 2004;9:15-23.

55. Chen J, Choe MK, Chen S, Zhang S. The effects of individual- and community-level knowledge, beliefs and fear on stigmatization of people living with HIV/AIDS in China. AIDS Care. 2007;19(5):666-73.

56. Zhao Q, Li X, Zhao G, Zhao J, Fang X, Lin X, et al. AIDS knowledge and HIV stigma among children affected by HIV/AIDS in rural China. AIDS Educ Prev, 2011;23(4):341-50.

57. Buber R, Gadner J, Richards L. Applying qualitative methods to marketing management research. UK: Palgrave Macmillan; 2004:141-56.

Corresponding author: ***Pei Lin Lua, 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, Terengganu, Malaysia.***

Email: peilinlua@unisza.edu.my

Received: 12 May 2012 Accepted: 17 July 2012