PRELIMINARY REPORT

Informal Caregivers and Their Coping Styles: A Preliminary Report

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ABSTRACT

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Introduction	There is a strong correlation between stress and the quality of care provided by informal carers. In this regard, an accurate understanding about factors contributing to stress among informal carers is crucial in order to find appropriate interventions to solve their problems.
Methods	A pilot study was conducted in October 2009 in the Klang Valley area, to test the instrument liability in the local context. In-depth interviews were conducted with two informal caregivers who are providing full-time care for their chronically-ill family members.
Results	Informal caregivers face multiple types of stress. A variety of factors such as financial problems, an unsupportive community, fatigue, the unavailability of social services to assist them and their inability to accept the fact that their loved ones are terminally ill, contribute to their stress.
Conclusions	Differences in factors contribute to stress, and lead to the adoption of different styles of coping strategies: emotion and problem focused coping.
Keywords	Informal caregivers – stress - coping strategies

INTRODUCTION

Informal care is always used to refer to care provided by the non-public sector; such as the private and voluntary sectors, and the "third sector" (e.g. family members, neighbor, community members) and clients who receive services[1, 2]. Conventionally, informal care is provided by untrained social network members (e.g. family or friends) and it does not involve any monetary compensation. It is a care that is provided on an unpaid basis usually from a feeling of love and a sense of obligation [3]. Informal care refers to *"...activities that provide unwaged and personal services particularly care within the domestic domain"* (Ungerson 1995: 32). It is different from formal or professional care which involves a group of professional personnel with specified tasks and skills, some form of fees, bills and salaries, a set of formal services and a set of procedures or rules to be conformed to. Informal care is rooted in attachment based on personal emotional involvement.

Informal caregivers are an important element of the Community Care Program in most countries including Malaysia. They are a source of informal care. They are individuals such as partners, spouses, parents, children and siblings who feel some emotional and/or obligatory bond with the person they are caring for[4]. As informal care is typically provided in a domestic domain, it is assumed that care providers are partners, spouses, parents, children and siblings who are associated through marriage and blood connections[5]. They are recognized as a crucial source of long-term care. Most informal caregivers work in the familial sphere (their own home and/or home of the care recipient). It is also preferably provided and delivered in a community environment. They habitually live in or live close to the care recipient. Informal caregivers play an important role in long-term care for their family members; especially after the patient is discharged from institutional care. Their tasks range from personal help (bathing, dressing, toilet needs), practical help (helping with housework and cooking, looking out for their safety, attending their monthly medical check-ups), emotional support (encouragement, a feeling of security) to providing companionship.

Caring for family members, especially old and sick parents, is associated with a norm of filial piety. Altruism and traditional obligations or duties have been considered as essential bases for informal care. Most social norms consider giving care to family members as a norm of reciprocity. Traditionally, members of nucleus family (e.g. mother, father, husband, wife, children, and siblings), members of the extended family (e.g. grandmother, grandfather, uncle, aunt, nephew, niece and cousins) and community members (e.g.

neighbors, friends) are expected to assist their chronically ill members. Even though close friends or neighbors sometimes provide the care, the family is still the most important locus of care in the informal care sector.

Empirical evidence confirms negative consequences of fulltime care-giving to ill or highly dependent family members on informal caregivers. Being isolated, without time for them, a lack of time for socializing with family and friends, failure to develop careers, unbearable financial problems, and failure to play expected domestic roles to other family members and physical inability to provide care to patients are common consequences of care-giving [6,7,8,9]. Due to this, the effects of care-giving on caregivers' wellbeing need to be carefully assessed. Attending effects could generate risk factors to health, both physical and emotional, and cause social strain amongst carers. This in turn may influence the quality of care given to care recipients. Thus, a study which can identify problems that contribute to stress among caregivers, is imperative.

The ways in which informal caregivers respond to their stress varied; depending on the coping strategy they adopted[10, 11]. Most caregivers face the problems and their stress alone silently conflicting their selves. There are also caregivers who try very hard in self-defense to gloss over the situation by denying and/or diverting the problems and stress faced to some other matter. Only a few fortunate caregivers can get appropriate assistance (in the form of social, emotional and financial support) from their extended family members, friends, neighbors, communities and formal social agencies such as the Social Welfare Department, Zakat Distribution Center, a community health clinic and non-governmental organizations (NGOs) in the community. This information then lead to the question regarding by informal caregivers coping strategies practice. Our curiosity about informal caregivers' well-being does not end here. The ways in which each strategy eases their problems or stress is further explored to identify the components of effective coping strategies.

METHODS

A pilot study was conducted in 2009 to explore the stresses experience by two informal caregivers and the strategies they adopted. The study also was intended to identify coping strategies practiced by informal caregivers.

A qualitative study, which utilizes the case study tradition, was conducted to gather data based on the outlined objectives. Individuals who were considered as primary caregivers for their sick family members and co-reside with the care recipients were qualified to participate in this study. This study involved only informal caregivers who take care of their family members who are

chronically ill. In this context, the term "chronically ill family member" is used to refer to patients who are discharged from institutional care, yet need fulltime care at home. Geographically, the investigation was concentrated only on the Kuala Lumpur and Selangor areas. A purposive sampling technique was used to get contact addresses of care recipients. The Medical Social Work Unit at the University Hospital, Kuala Lumpur and Social Welfare Department, Kuala Lumpur assisted us with contacts. In-depth interviews, by using focused technique were conducted. This technique requires researcher and respondent to build a good relationship before the latter feel confident enough to share his/her experiences, feelings, problems and hopes with the researcher.

Interview guideline was constructed by taking inspiration from past studies. Topics guidelines were based on; profile (caregivers, patients, and families), the period of care, daily routine care, the stress experienced, how to deal with stress (coping), changes after an action, and other issues that caregivers want to discuss. Questions being asked were in the form of an open question. Topics guidelines were prepared in order to ensure that the interview process was run by the scope of the study [12]. Two respondents in this pilot study were named as Respondent A and B. Respondent A is a 44 year old man who is care-giving his grandmother (70+ year old), who has been diagnosed with diabetes, Alzheimer and urination incontinency. Respondent B is a 32 year old mother who is care-giving her son who has been diagnosed with a brain tumor since he was 8 year old (now he is 10 year old). The findings from this pilot study are reported in this paper.

RESULTS

Care-giving is a very demanding, laborious and stressful job. It is more arduous when any form of assistance is absent. It has significant consequences on all aspects of caregivers' lives[13]. Thus, it is extremely important to treat any inconvenience of care-giving tasks as it may act as a root to stress among caregivers. This is what we intend to do: we try to draw together difficulties and problems faced by our respondents in care-giving their sick family members. Two respondents in this pilot study were named as Respondent A and B. Respondent A is a 44 year old man who is care-giving his grandmother (70+ year old), who has been diagnosed with diabetes, Alzheimer and urination incontinency. Respondent B is a 32 year old mother who is care-giving her son who has been diagnosed with a brain tumor since he was 8 year old (now he is 10 year old). The findings from this pilot study are reported in this paper.

The preliminary findings show that both respondents have multiple types of stress. Financial insufficiency is the main source of their stress.

Respondent A, for instance, is married and has 6 children (ranging from 5 to 15 years of age). He is working as a lorry driver with a monthly salary of RM1400. He is renting a small flat in the heart of Kuala Lumpur with monthly rental payments of RM300. His income is inadequate for his family's monthly consumption even though his wife (a fulltime housewife) manages to run a small business (selling puffs) in the afternoons to earn extra income for the family. His grandmother needs to use disposable diapers for her incontinence. This contributes to an extra increase of their monthly expenses. Although his grandmother receives a sum of RM300 monthly cash assistance from the Social Welfare Department, it is still inadequate. In order to get extra income for the family, respondent A does extra time work. He gets paid around RM600 for this extra work. Yet, it still fails to make ends meet. Respondent's A health is depreciating, being fatigued with his jobs, anxious about his financial situation and worried about his grandmother's illness. His asthma is worse because of the stress.

Respondent B also reports critical financial stress. Her family monthly income is dependent on her husband's income, as he is the sole breadwinner. She recently chose to leave her fulltime job as a clerk at a commercial bank because she needs to give fulltime care and attention to her son. Her husband works as a technician at a small factory with a monthly salary of RM1400. Her household consists of 4 persons Her household monthly consumption comprises RM350 for house rental and RM250 for the family car monthly payment. They apportion the balances, approximately RM600, for milk, disposable diapers for their youngest son, food, utilities, and hospital bills. Each medical follow-up appointment for her son costs her about RM50 for taxi fare. Also, her son needs 2 to 3 medical check-ups in a month. In the absence of any financial assistance, she withdrew her Employees Provident Fund (EPF) savings to settle the hospital bills. Fortunately, starting last year, her son's chemotherapy and medication costs are being funded by National Cancer Council (MAKNA). This helps reduce part of their family burdens and stress.

Other than financial stress, both respondents are also developing emotional stress, of a very different magnitude though. Two antecedent factors contributing to the stress are their social environment and their mental defenselessness. Both respondents are living in a social environment that lack support and symbolic understanding. This is characterized by unsupportive communities, a disintegrated neighborhood, a lack of social facilities to relieve their fatigue, and an unavailability of social services to assist them. The minds of both respondents are ill-equipped to accept the fact that

their loved one is terminally sick. Respondent B, for instance, personally reported that emotion is the most stressful event for her. It had never crossed her mind that her son would have cancer. She could not accept the fact that her son would suffer with this deadly illness. She feels sorry for him. Her son is still schooling. He always makes himself absent because he claims that his friends are laughing at him because of his hair loss; the side effect of chemotherapy. Her neighbors do not lend a helping hand. They stay away from the respondent's family and also prevent their kids from playing with the respondent's son. They are also making her burden heavier by blaming her. They accuse her saying that her past sins contributed to her son's illness. Earlier, she could not accept the accusation. However, she now has learnt to accept it and sees it as a test given by God. She tries to motivate herself with this self-affirmation*" Who are they to punish us?"* Moral support from her husband and close relatives makes her stronger emotionally.

Respondent A's experience however, is quite contrary to that of Respondent B. Respondent A reported that he infrequently has emotional stress. Even so, his wife will be the first person to know that. He accepts this situation as his fate. He does not regret taking care of his grandmother. It is his responsibility to pay his respect and love to his grandmother. His grandmother has loved him so much. She took care of him when he was young; even though his parents were around. He perceives the care given as his reimbursement of her grandmotherly love and care when he was young. He has a very helpful wife and children. His wife has been his true friend and soul-mate throughout this difficulty. They are close to each other. They share the care tasks equally and always talk about their stress. They are trying to provide as much as they can afford to the grandmother; even though his extended family members infrequently give any financial and physical assistance. Nonetheless, he is hoping that they can give him some financial assistance to bear the treatment and medical costs, which alone costs him more than RM500 per month. He thinks his family should understand that this is a family responsibility, not his alone.

Contrary to Respondent B, Respondent A has very supportive and understanding neighbors. They help him by taking his grandmother to the nearby public clinic for her monthly check-ups when he is working. Inevitably, there are some neighbors who try to stay away from his family. They claim that being close to his family will affect them. They presumed that he will ask for help or borrow money. Because of this, he never asks for any help from these unsupportive neighbors. He never seek professional help because of time-constraints and his lack of knowledge about where and how to get that help. For him, as long as his grandmother feels comfortable staying with him,

and as long as his wife is beside him, he can manage the care of his grandmother. *"Whatever it is, this is my compulsory obligation"*- this is his statement of relief.

Findings also indicate that both respondents are experiencing a different process of stress due to differences in their social background. In terms of education, Respondent B is found to be more knowledgeable than respondent A. Respondent B attained a STPM level of education; whereas Respondent A is only a SRP holder. Respondent B's social networking also is more well-informed, compared to Respondent A's. Her previous employment as a clerk for a commercial banking company has given her friends who are knowledgeable about her son's illness and who also help her access information and support. She constantly attends counseling and family-group therapy sessions which are conducted by NGOs working with cancer victims/family members. The activities, especially the family-group therapy are very helpful in reducing her emotional stress. In these self-help activities, she can share her experiences, her worries, her anger and her strengths with other parents who are having the same problems. She recently joined as a volunteer with the organization.

In terms of physical ability, Respondent B was found to be more vigorous than respondent A. Respondent A is not only older than Respondent B; he also has a health problem. He is an asthmatic. He cannot perform most of his care-giving tasks. He is lucky to have grown-up and healthy children (boys and girls) to help him and his wife to take care of his grandmother and to perform most of the heavy duties (e.g. bathing her, changing her clothes, toileting, feeding, giving medication). According to Respondent A, his grandmother needs a bath twice a week. Though her room is next to the bathroom, Respondent A wife and daughters still need assistance to take her to the bathroom. This is where the boys' help are important. *"They are like the "hauler" for their grandmother. I thank God for giving me strong, healthy and kind-hearted boys"*, said Respondent A's wife when she was interviewed. The girls also come in handy. They help their mother do most of the "personal need" duties (e.g. cleaning, changing diapers and clothes) and giving medicines to their grandmother.

Feedback received from both respondents makes us understand that caring for a child is far more demanding, compared to an adult. According to Respondent B, she needs to be with her son all the time, especially when he is in a critical situation. She not only has to do the entire heavy task, such as bathing, toileting cleaning, monitoring his medication intake and feeding alone. She also has to attend his tantrums, especially after the chemotherapy treatment. The other thing that she constantly has to do is to empower his son to

struggle with his sickness. She said *"...It is like telling a lie to him. Telling him that he will get better after the chemo is a struggle. I cannot explain better when he has to undergo one chemo to another chemo"*. She added, *"This is killing me, softly!"* Compared to Respondent A's grandmother, Respondent B's son cannot accept the fact that he is sick and not be like other normal children of his age. This drives him to question his mother with difficult and sad questions, such as: *"Will I live long?"*, *"Can the doctor help me?"* *"Can God help me*? Whereas, Respondent A's grandmother seems "settled" – she accepts her illness due to old age and believes that this is a transition between life and death.

Concisely, findings from our pilot study confirmed that care-giving to terminal ill family members is stressful, whether emotional or physical. This is more severe if the family does not have strong financial back-up, support from family members, friends and neighbors or lack formal and informal support services and assistance in their communities. They need their family members, friends, neighbors and communities to understand them and to support them. These components play dual functions or roles. They can be a source of stress, and at the same time they can be a resource to combat the stress, as well. The ways in which all these resources react to the caregivers and the magnitude of their availability to the caregivers is affecting their coping- style practice.

DISCUSSION

Lazarus and Folkman [11] categorized coping styles in two groups. They are emotion-focused coping styles and problem-focused styles. Each style has its own strategies. Emotion-focused coping style is defined as an inner coping style which enforces individual's feelings or emotions. It aims to reduce emotional stress. The six strategies of the emotion-focused coping style are social support, self-control, positive reappraisal, accepting responsibilities, escaping-avoidance and distancing. On the other hand, the problem-focused style is an alteration of the stressful situation which aims to solve the problems causing the stress. Two strategies of this style are confrontation problem-solving and planned problem-solving.

Our study reflects that informal caregivers practice both style of coping strategies, in responding to their stress. However, they are more likely to prefer practicing the emotion-focused coping style, compared to the other style. Seeking support from those who are close to them, especially their spouse and family members, is their main coping style. Social support strategy is defined by Carver et al. [14] as seeking support in terms of morale, sympathy and understanding. Respondent A seeks support from his wife, while respondent B seeks support from her husband.

Outside the family circle, they also seek assistance from either public agencies, self-help groups or voluntary agencies. Support from these agencies is in the form of financial help, subsidized treatment, emotional support, and social networking.

Positive reappraisal also plays an important role in reducing caregivers' stresses. This strategy refers to an individual who is experiencing stress and restructuring the problem to become a positive thing [15]. Religion is a crucial agent of positive reappraisal [16]. In the context of the 2009 study, for example, both respondents view their stresses and problems as their God-given fate. As good believers, both respondents believe that this is a test by God. As Muslims also, they believe that every single incident that happens is tested and written by Allah (God) in ensuring their faith in religion. This allows them to accept the burden and the stress. Carver et al. [14] explained that people might use this coping style when under stress for widely varying reasons, religion as a source of emotional support, as a vehicle for positive reappraisal or as a tactic of active coping with a stressor. They also learn to accept social norms and the responsibilities of being a mother and a grandson. They feel obliged to take care of their sick family members. As a mother, taking care of her own child is seen as a traditional role; no matter what, when and how. Learning to accept those social mandated obligations helps in reducing their stresses.

They are also coping by distancing themselves from the unsupportive neighbors. They are ignoring neighbors who judged them. Distancing is a coping strategy in which the individual make an effort to minimize or avoid thinking about stressful situation [17]. However, this style of coping is less efficient when serious problems occur[18, 17]. Serious problems demand serious remedial action. If the problem is ignored, it may generate other problems or develop into more serious problems, which later result in more distressful events[19]. This is the weakness of the distancing coping style. Compared to the distancing coping style, the positive reappraisal style is much more efficient because it changes the stressful actor's emotions from negative to positive. This is contrary to the distancing style, in which it changes the stressful actor's emotion from being positive to negative.

We do understand that provisions of care within households definitely had dramatic consequences on the financial situation of the co-resident caregivers' households. It means having either to give up paid employment or to shifting to part-time or casual work. Being full-time caregivers demands a lot of time. The likelihood of participating in most forms of fulltime jobs diminishes. This has a significant impact on their earnings and income level. Many caregivers fall

into the level of low-income households[20]. Due to this, many of them have to rely on public income support. However, public cash assistance manages only to reduce part of the stress, especially the financial stress. It fails to compensate caregivers' financial position sufficiently [21]. It does not also take into account the additional costs incurred from caring [20]. Cash and assistance in-kinds, whether they are public or charity-based are remedial assistance. Thus, some form of intervention which may reduce the financial consequence of caring is badly needed.

According to Corti and Dex [22], a flexible employment policy for full-time informal caregivers has been very practical. In most developed welfare-states, a set of employment support measures has been implemented to help informal caregivers remain in work; rather than take a break from paid employment. The supports are designed to facilitate the caring activities. Initiatives such as setting up a Workplace Support Group with the involvement of trade unions in every workplace, a specific agreement which covers the needs of caregivers for family (e.g. Family Leave, Compassionate Leave) in every workplace, collaboration efforts between employers and voluntary organizations in delivering various workplace support schemes, either through direct financial assistance or technical support, opportunities to work part-time or share a job without loss of responsibility, seniority or rates of pay, and provision of annual entitlements to a specified number of days of paid leave for "family" or "domestic" responsibilities have been response to caregivers problems successfully [23]. All those interventions may be considered and fully scrutinized for their suitability to the local context.

The preliminary study also indicated that social, emotional and physical strains had equal impact on most caregivers' lives. Although the study had identified the caregivers' need for information, practical help and emotional support, their main need was for the community to recognize their needs and lend a hand based on the identified need. Caregivers' needs, such as recognition of their contributions, services tailored to their individual circumstances, services which reflect an awareness of different racial, cultural and religious backgrounds, opportunities for a break, practical help, someone to talk about their own emotional needs, information about benefits and services, and about conditions of the person they care for, and income which covers the costs of caring, opportunities to explore alternatives to family care, all may sound so demanding and very difficult to do. Scanning the needs, it shows that all the caregivers's needs required some form of support from both the formal and informal sectors of care. Hence, the best possible way to help

caregivers to fulfill their needs is to suggest a partnership between the formal and informal sectors. This area needs to be explored further.

Informal care development in most countries, including Malaysia, is closely related to the Community Care movement. In Malaysia, the Community Care Policy of 1990 recognized the importance of informal care as one of the assumed sources of long-term care, alongside the institutional care for the chronically ill. The policies introduce a set of arrangements to ensure that there are informal care sources, especially family, friends, neighbors or partnership with public agencies to form a network of home-based care or community- based care. It is also referred to as care by community to community.

The movement of community care policies in most welfare states has contributed to the development of social services to support informal caregivers' needs. In the United Kingdom, for instance, the National Health Services and Community Care Act of 1990 required local authorities to design packages of services to meet the assessed needs of the caregivers. The Carer Support Programmes were identified as one of the services. The program comprises four categories: alternative care for the dependent in the home, alternative care for the dependant away from home, information and advice for the caregivers about services, benefits and how to handle the caring situations; and, support and advocacy for caregivers. These services were set up either by local voluntary agencies, self-help organizations (with a guide from the state), or collaboration amongst those three sectors. The alternative care for the dependent in the home program and the alternative care for the dependant away from home program give chances for caregivers to take a break. Sitting Services, Respite Care, Relief Care Schemes, Good Neighbor Programme, day centers, day clubs, Host Family Schemes and many more services help caregivers with the physically difficult tasks, and to look after the dependant for several days longer. These innovative approaches used flexi services to suit carers' time with their other duties. For example, day centers and respite centers were open at weekends, which is a particularly stressful time for most carers. Besides having a break and reducing the pressure on the carer-dependant relationship, caregivers can use this adjustable time to cope with their paid job. Both respondents from the pilot study were likely to experience not only financial deprivation, but also exhaustion, loss of privacy, fear, embarrassment, anxiety, grief, and daily irritation, loss of freedom, social isolation, worry and guilt. Barusch [24] referred to carers who live with these situations as the "hidden patients". Information and advice for the carers about services, benefits and how to handle the caring situations and, support

and advocacy programs for carers may be helpful for reacting to these situations effectively. Carers Resource Centers, Help Line, Home Visitors, Carer Support Groups, Counseling Services, Carer Support Workers, Carer Consultation Workshops and information packs provide practical help to which they could refer, meet others and talking about their situations.

Care-giving depends on the availability of human resources who are providing the care. The third sector resource, especially volunteers in the community could be utilized to provide a valuable service to informal caregivers. We again quote the United Kingdom experience, the National Health Services and Community Care Act of 1990 acknowledged volunteer's ability to assist carers through its Demonstration Districts for Informal Carers Programme. In the program, they established funded voluntary organizations to provide a range of support services for informal caregivers. The Tavistock Institute of Human Relations who monitor, evaluate and identify the outcomes of the program found that 43 new services were developed by different agencies, ranging from large professional voluntary organizations to small caregivers in self-help groups. Collaboration and joint work between agencies involved in the provision of support to informal caregivers has been established at the local parish level. This intervention, which has proven helpful in helping informal caregivers, may be considered seriously to be applying to our context.

CONCLUSIONS

Findings presented in this paper are feedback from our pilot study. Hence, it is too early to discuss proper interventions precisely. However, the findings do give us some idea about the coping strategies favored by informal caregivers. Further interventions may act as a framework to a more comprehensive social provision which could provide an effective response to our local informal caregivers' stress.

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