

Informal Caregiving: Empowering Social Support Programs by Employers

Penjagaan Tidak Formal: Memperkasakan Program Sokongan Sosial oleh Majikan

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ABSTRACT

The problems faced by people providing informal care to family members with chronic illness has not been discussed thoroughly in Malaysia. This research has therefore been carried out with the aim of exploring types of informal social support currently practiced and related issues. It is based on a qualitative analysis of the interviews of five informal caregivers responsible for chronically ill family members in Kuala Lumpur. All respondents have struggled to provide the financial and emotional support required, especially as four were unemployed. These respondents were dependent on the family breadwinner, relatives and/or agencies for their daily needs, and also for the costs of medical treatment. They were physically able to work, but had chosen to focus on giving care instead. Some of the respondents had worked previously, but resigned after the condition of their care recipient had worsened. As a consequence, the respondents were facing financial hardship. Thus this analysis proposes that employers should incorporate social support programs into work contracts to enable better working hours and more flexibility for those staff engaged in informal care. By adopting this social support program, it is hoped that informal caregivers could have more financial independence and be less reliant on government agencies and families for financial assistance.

Keywords: Informal caregiving; chronic illness; social support; social support program; employers' empowerment

ABSTRAK

Penjagaan tidak formal terhadap pesakit kronik tidak dibincangkan secara terperinci di Malaysia. Oleh sebab itu, sebuah kajian yang bertujuan untuk mengenal pasti jenis sokongan sosial yang dipraktikkan oleh penjaga tidak formal telah dijalankan. Kajian kualitatif yang menggunakan metod kajian kes telah dijalankan dalam kalangan penjaga tidak formal yang menjaga ahli keluarga mereka yang sedang menghidap penyakit kronik. Seramai lima orang penjaga tidak formal di Kuala Lumpur telah pun ditemu bual menggunakan teknik temu bual mendalam. Dapatan kajian menunjukkan kesemua penjaga tidak formal yang terlibat telah menggunakan strategi daya tindak sokongan sosial dari segi kewangan dan emosi serta empat daripada mereka tidak bekerja. Mereka bergantung sepenuhnya kepada pencari nafkah di dalam keluarga, saudara-mara dan/atau agensi dalam memenuhi keperluan harian mereka dan juga kos rawatan. Secara fizikal, mereka mempunyai kemampuan untuk bekerja tetapi mereka memilih untuk menumpukan sepenuh perhatian kepada ahli keluarga mereka yang sedang menghidapi penyakit kronik. Sebahagian responden sememangnya pernah bekerja tetapi memilih untuk berhenti kerja selepas keadaan ahli keluarga mereka yang sedang menderita penyakit kronik itu semakin membimbangkan. Artikel ini menyentuh kepada program sokongan sosial yang sepatutnya disediakan oleh majikan termasuk faedah pekerjaan, waktu bekerja dan kemudahan cuti yang diperuntukkan khas kepada penjaga tidak formal. Melalui program ini, diharapkan penjaga tidak formal akan mempunyai lebih masa untuk mencari pendapatan kewangan tanpa perlu bergantung kepada agensi kerajaan.

Kata kunci: Penjagaan tidak formal; penyakit kronik; sokongan sosial; program sokongan sosial; pemerkasaan majikan

INTRODUCTION

Informal caregivers are the main human resource in the activity of social care. The demand for informal caregivers has increased over the last three decades (Cassie & Sanders 2008). According to them, this demand is the result of some factors such as

demographic transitions in a society from rural to urban area. Thus, the informal caregivers need to cooperate with professionals from formal sector (doctors, nurses, family social workers, welfare officers and counselors) in playing their part in caregiving. Furthermore, giving care is always associated with physical, psychological,

financial (Collins & Swartz 2011) and mental stress (Cassie & Sanders 2008). Therefore, they should be directed to appropriate social support program. This type of program needs to be strengthened in order to ease their stress, burden and depress (Cassie & Sanders 2008).

Social support is not an easy term to define as every perspective and field of knowledge will define it differently (Williams, Barclay & Schmied 2004; Cooke et al. 1988). An effort to define this term towards the social concept should be consistent with the field of knowledge. Associated with this, the researchers will explain the concept of social support.

Social support is always referred as "... support which is provided by other people and arises within the context of interpersonal relationships" (Hirsh 1981: 151) and "support accessible to an individual, group, and the larger community" (Lin et al. 1979: 109). Cobb (1976: 301) defined social support as "... the individual believes that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations". From these definitions, it can be understood that social support is a feeling or an emotional feeling that one is cared for, appreciated and respected in one's communication network.

On the other hand, social support is closely related to the social network concept. That is why, social support has always been seen and accepted as a relationship between individual and family members, friends, neighbours, office-mates and also other organizations around them that can provide and give assistance when needed (Hall & Wellman 1985). Therefore, social support can be defined as coming from the interaction between individual and surrounding social networks (O'Reilly 1988). Because of that, Hall and Wellman (1985) suggested that a social support program should look into the characteristics of the social environment in detail. These characteristics are socioeconomic status and interpersonal relationship. This article will discuss these characteristics of the informal caregivers by looking at the social support program that can be implemented by the employers to them. The issue of employability among informal caregivers needs to be discussed further because it is related to financial and emotional support. In fact, not much research has been focused on this issue pertaining to the informal caregivers locally. This study seeks to answer the following questions: What types of social support are the informal caregivers suffering? And how to empower the social support program by employers for them?

METHODOLOGY

A research has been done to explore the type of social support that has been practiced by them to overcome the stress that they experienced. In achieving the objective,

a qualitative study using a case study has been used. This is because, through case study, information on the experience that the informal caregivers went through in taking care of their family members with chronic disease and their coping strategies that have been practiced, could be gathered. The type of case study that has been done was multiple case studies as it was seen to be able to give a thorough understanding about the stress that was experienced by the respondents of this research, and also the coping strategies that have been opted by them.

Five respondents participated in an in-depth interview sessions in their own home. They were chosen from a patients' list who obtained services from the Department of Medical Social Work, University Malaya Medical Centre.

The selection of the respondents was done through purposive sampling by using a criterion sampling technique. In this research, the researcher did not limit on the age of the informal caregivers. An important criterion in qualifying a respondent for this research is, the person must be the primary caregiver of a family member with a chronic disease and remain together. Due to that, this research only involves five cases by taking into consideration the criterion and the availability of the respondents.

A guideline for an interview was built by taking some inspiration from literature reviews from past researches such as Rodehaver (2008) and Kerr and Smith (2001) on the caregiving experience of the informal caregivers. The type of question is an open-ended question that requires the respondents to answer subjectively and clearly (Silverman 2010). On average, each respondent had three meetings. The location of the meeting was in the respondent's own home as every bit of their time was needed in supervising and looking after the patient. A tape recorder and a note field were used in recording every meeting. The duration for each interview session was from 45 minutes to 1 hour 30 minutes. For each session that had ended, a verbatim transcription was done within 24 hours to make it easier for the researchers to revisit and analyse every meeting, within the duration. Information collecting ended when the interview hit its saturation level. Saturation point happens when no more gains of data is found from the interview and/or the respondents are simply doubling the information that was already found in the previous interview (Ritchie & Lewis 2003).

Manual transcription analysis was used to analyse the data. The researchers did not use any software in analyzing data as our desire was to really understand by heart the experience undergone by the respondents, and therefore could check the data captured. The researchers applied the reading repetition technique in ensuring the transcription was understood before forming a theme. This technique also helps in ensuring no information or research questions are left out. In analysing the

data, open coding was first employed to develop a general overview of the interviewees’ experiences. From the original data, codes were generated in terms of the various concepts and issues that emerged. Then, selective coding was conducted to systematically analyze the data and identify the themes.

to men. The norm of the culture among the society, that has put the responsibility of taking care of their ill family members to the shoulders of women, has contributed to this.

Age-wise, most of the research respondents are between the ages of 25-58 years, whereas from marital status wise, four of the caregivers in this research are married and one is single. Two of the caregivers, are taking care of their son, and the rest are taking care of their own mother, brother and husband who have been diagnosed with different chronic diseases. Table 1 is a socio-demographic profile of the respondents.

FINDINGS

SOCIO-DEMOGRAPHIC PROFILE

Five respondents were interviewed. All of them are women. This has indirectly confirmed the reality of more women becoming an informal caregiver compared

Respondents	Socio-demographic profile
Ah Siew (not a real name)	<ul style="list-style-type: none"> • A mother (50 year old, Chinese) to a son diagnosed with Spinal Stenosis. Married with three children (20-23 years old, and patient is the first child). • Originally from Johor but stays in Kuala Lumpur after SPM. The highest education background is SPM. • Full-time housewife and dependant on her husband as the breadwinner (selling vegetables, fish and meat). Profit is RM100-150 per day on average. • Monthly expenses is around RM2300 (house rent, utilities, beverages, special milk and diapers for patient). • Working experience: Clerk at a law firm before married. Intent to work to help her husband in medical cost.
Ah Lin (not a real name)	<ul style="list-style-type: none"> • A wife (30 year old, Chinese) to a husband diagnosed with Idiopathic Scoliosis. She has a son age 10 years old. • Originally from Kajang, Selangor. The highest education background is SPM. • She is working at a restaurant after her husband’s condition becomes worse and cannot work anymore. Daily payment is RM40. • Monthly expenses is around RM1110 (house rent, utilities, beverages and car loan).
Ah Peng (not a real name)	<ul style="list-style-type: none"> • A sister (25 year old, Chinese) to a brother diagnosed with Idiopathic Scoliosis. • Staying with the patient and her mother (65 year old) in Cheras PPR. The highest education level is SPM. • Unemployed and fully taking care of the patient and mother. Monthly expenses is around RM500-RM600 (House rent, utilities and beverages). All the expenses are supported by her sister and second brother. • No working experience. Intent to work as she is still young and capable to work.
Ana (not a real name)	<ul style="list-style-type: none"> • A mother (54 year old, Malay) to a daughter diagnosed with Tuberculosis Spine (TB Spine). Married with six children (24-35 years old, and patient is the youngest kid). Three are married and working in public and private sectors. • Originally from Kuala Lumpur and the highest education level is SPM. • Full-time housewife and husband is a taxi driver with irregular income around RM1000-RM2000 per month. • Monthly expenses is around RM900-RM1000 (house rent, utilities and beverages). • Working experience: Cleaner before her daughter was diagnosed with TB Spine. Intent to work to help her husband in medical cost.
Hema (not a real name)	<ul style="list-style-type: none"> • A mother (44 year old, Indian) to the only child diagnosed with Idiopathic Scoliosis. • Originally from Klang and the highest education level is SPM. • Unemployed and fully dependant on her husband as a breadwinner with an income of RM1000 per month. • Monthly expenses is around RM600-RM8000 (house rent, utilities and beverages). • Working experience: Sales girl before her child was diagnosed with Idiopathic Scoliosis. Intent to work as she is still able to work.

TYPE OF SOCIAL SUPPORT

This research found that all the respondents have coped with social support. Social support that they need are financial and emotional support, whether from nucleus family members or the extended family, or from their neighbours. The respondents, however stated that they expect more from their family members to understand and help them, rather than from their neighbours. The stress that they face will lessen a little bit when the family members understand and lend them a hand; whether from material or emotional aspect. McCubbin, Thompson and McCubbin (1996) explained that coping strategy that involves family members is known as family inner source strategy. It is a strategy to help individuals; that is their own family, to adapt to the crisis among their own family. This could be done through cooperation and understanding among family members, family member's support, and family's financial state stability that could all strengthen the family ties.

This research found out that, the first type of support that the respondents expect and hope from their family members is emotional support. Examples of emotional support that they need are the act of concern for the families by visiting or calling the family of the informal caregivers. In addition, they mentioned that when their family helped a lot by giving emotional support, they have someone to chat and express their feelings. As Ana mentioned:

Ana: My family is always visiting me and the patient, or sometimes they will only call me if they do not have time to visit. I do not hope for any financial assistance, asking of us is ok.

Hema: Sometimes, my family comes here. They are kind to me and my son. They can just afford an emotional support, not in-cash aid.

Nevertheless, financing is the main support they need as the living and medical cost is increasing. Financial support is also seen as necessary and has to go hand in hand with emotional support. Financial support needed are in the form of financial aid and daily needs such as rice and other patients' necessities like medical drugs. As Ah Peng and Ah Siew mentioned:

Ah Peng: My siblings pay all the monthly expenses. Even though sometimes it is not enough for patient's necessities, but I am praising God for having them to support. I understand, they have their own commitment, especially living in Kuala Lumpur. It is fine for me. Better than never!

Ah Siew: The living cost is increasing day by day. We have difficulties every month, especially in terms of patient's necessities like diapers. All this is very costly. We do not get any help from government agencies.

In this study also, one of the respondents had to work because the husband who was the breadwinner of the family had fallen sick. Ah Lin said:

I have to work after my husband's condition worsens and he has been laid off of his work. Now, he stays at home and I am working at the restaurant.

So, this is an indication that they actually have the ability to work. There are also respondents who originally worked, but, had to be laid off because of taking leave too often. This happened to Ana and Hema. They said:

Ana: I was a cleaner before my daughter has been diagnosed with TB Spine. But, I have been asked to resign because too often taking leave and time-off. I'm still able to work and I want to help my husband who is only a taxi driver and earning uneven income.

Hema: I was a Sales Girl before my only child diagnosed with Idiopathic Scoliosis. It has been eight years now since I have been asked to resign. I did try to work at other places but had been asked to resign when I always took leave. So, what else can I do? Many employers do not want an employee like me. Eventhough I still can work.

Majority of the respondents expresses a desire to work because they are in good health and able to work. For instance Ah Peng, who is still young:

Ah Peng: Yes, I want to work! I am still young and able to work. Even though my siblings support us in term of financial, but, how long can they support us? I have to think for my future also.

However, this problem arises due to the lack of employment opportunities. Cassie and Sanders (2008) mentioned that lack of employment opportunities happened when the employers cannot tolerate to informal caregivers' needs such as absenteeism, working interruptions and decreased in productivity. According to Earle and Heymann (2011) and Arksey (2002), these problems can be overcome if the employers can respond to informal caregivers' needs in terms of flexible working hours and type of leave given to the informal caregivers when needed. These studies have explained why caregivers need to work to support the family income. This will be discussed further in the next section.

DISCUSSION: EMPOWERING SOCIAL SUPPORT PROGRAM BY THE EMPLOYERS

The results show that the respondents faced financial problems due to inadequate income which in turn causes the life of the respondents' family to always be

inadequate, deficits of needs or economically insecure. Thus, most of the respondents of this study had to rely on financial assistance from the Social Welfare Department, Baitul Mal, or financial help from family members. But, how long will they have to depend on them?

Although informal caregivers are seen physically able to work, they themselves need to think properly as these patients need continuous attention. If they work, what about the patients who are left at home? If they want to take a paid caregiver, they cannot afford anyway. If they want to send patients to the care centre, they have difficulties in accessing it. These problems are also experienced by respondents described by Mehta (2005), in which he explained that most of the informal caregivers (family) in Singapore are from low income group and they are in need of assistance. On average they are not able to send some patients on day care services as most of the care service centres in Singapore is undertaken by the private sector which involve fees/ cost and is expensive.

In this regard, apart from some form of financial assistance and material support, employment opportunities for informal caregivers also needs to be upgraded. This is because these people are still able to work physically as stated by Ana, Hema, Ah Peng and Ah Lin. However, the responsibility of caring for patients, stunt their desire to work. Furthermore, health care of the patients may have a significant impact on the family. It requires resources such as financial, time and energy. Monetary assistance from the Social Welfare Department would ease the burden of the caregiver's even though it would not resolve their financial struggle. Thus, caregivers do need to have a stable job as well as given a flexible working time in order to take care of the patient/family member. Flexible working time is a house works adjustment with a full-time job (Noor Rahamah 2013), which they can adjust their time in taking care of the patient or care recipients to fit with their full-time job in the office. This flexibility include the establishment of workplace support groups to address the needs of caregivers' families, opportunities to work part-time or share a job without loss of seniority or rates of pay, flexible working arrangements and a provision of annual entitlement to paid leave for family responsibilities (Siti Hajar et al. 2014; Gordon et al. 2012).

This flexibility has not been spelled out clearly in any policies or regulations that governed private or public sector employees. Employment Act 1955 covers private sector employees while the General Orders governs the private sector employees. There are comprehensible policies on leaves such as annual leaves or sick leaves. However there is no clarification about caregivers' flexible working time from any of the acts and regulations. In General Orders for example employees are responsible to require official permission if they were to leave the office during working hours.

In the United Kingdom, the jobs with flexible hours and paid leave will be emphasized in Employer Relations Act (1999). Emphasis was made to prevent informal caregivers ostracized by the society (Arksey 2002). Among the strategies that can be implemented by employers are introducing flexible working hours for employees who are also informal caregivers and family members of the sick as well as the provision of partial or full paid leave and other forms of support such as counseling (Arksey 2002). Flexible working hours seemed so appropriate to be applied to the informal caregivers. This is because, caregivers can choose the time for them to start or get to work and finish work (Arksey 2002). Arksey also stated, in his study, employees who take care of sick individuals are better at working on flexible hours. 10 out of 13 employers in his research facilitate this system of flexible working hours. Through this system, the work can be calculated based on weeks. In addition, employers may also provide opportunities for the informal caregivers to work from home, especially jobs that involve office administration.

Surprisingly, Multinational Corporations such as IBM and Citibank are serious in implementing the mobility program that provides flexibility for working mothers to work from home in promoting work-life balance. However the government needs to revise the Employment Act 1955 and General Orders if such program is implemented. Not only that, trust and loyalty of both parties; employers and employees are critical for the success of the program. As it is right now, the mobility program was undertaken only by certain companies as their special policies.

Earle and Heymann (2011) also explained the importance of informal caregivers employer to take care of the health of informal caregivers. He added that in the United States, the informal caregivers who are mentally and physically healthy is related to a supportive employer. The support given is in terms of granting paid leave to employ informal caregivers. Two programs that can be selected by the employer in the performance of this support is through the medical insurance leave by an employer. Medical insurance leave program is essentially given by the contribution of informal caregivers themselves for the work. So, this insurance can be used for patient care leave. Implementation of this program is seen very similar to social security programs implemented by the Employees Provident Fund and Social Security Organization in Malaysia. The difference is the individual recipients contribute in these schemes is patient and it is not acceptable for those who are taking care of sick people.

In addition, support for informal caregivers should also be considered by employers. Environment-friendly keepers with good facilities to support this group can provide a positive impact on the quality of work of informal caregivers. Employers in the United Kingdom in Arksey's (2002) study has implemented this strategy by providing support facilities such as counselling and

financial assistance. Financial assistance in this matter is through fundraising undertaken by the employer. In Malaysia, not all employers provide such facilities because it is not something that must be implemented by the employer. Similarly, it is not stipulated in the employment act.

There are no specific regulations that explain thoroughly regarding employers' responsibility in providing compassionate support for caregivers. Compassion in this context is to provide some flexibility for caregivers in terms of flexible working hours, stratified wages or even to work from home.

The above programs are suitable for the informal caregivers who are working or want to work. Enforcement of employment policies should give priority to the informal caregivers, since many informal caregivers are women who are often associated with a variety of roles. Statistics show the number of women working in Malaysia stood at 4,017.3 million (Department of Statistics 2010). Diversity of roles played by women, if not given attention can affect their health and well-being (Earle & Heymann 2011).

Employment is not only important for informal caregivers, but for every individual as it contributes to the family income to meet daily needs. Thus, every informal caregiver who is able to work should be given more employment opportunities. The way in which employment opportunities for this group can be opened as wide as possible, requires detailed scrutiny and amendment of human resource policies and existing employment act. This point should also be explored in more depth by future researchers.

SUMMARY AND RECOMMENDATIONS

This study shows that the informal caregivers need social support programs in term of employability. At this stage, the proposal is in terms of improvement by employers and government policy. For employers, the opportunity for the informal caregivers to work with flexible hours should be given as they personally want to work and are able to work. This is because, in this study, it was found that informal caregivers are still able to work. Unfortunately, the limitations of their work outside the home, prevent their desire to work. Therefore, it is highly recommended that employers provide opportunities for informal caregivers to work from home, so that they can still take care of patients.

Apart from working at home, the employee in charge of a sick family member should also be given the option to work in and out of time. With this option, they can plan their care schedule, daily routine and working hours as well. So, the informal caregivers who work will only be paid based on their period of work either by the hour/time or number of days. Malaysian employers should cooperate with workers and trade unions to find

ways to build consensus in policy-friendly employment and family needs that will provide benefits to both parties. Policy and Employment Act should be should empathise the needs of workers who are at the same time are caregivers of a sick family member, may be explored more detail in the formulation of appropriate policies and act in our social context.

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