Projecting social support needs of informal caregivers in Malaysia

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What is known about this topic
• Caring for a family member ill or with a disability may adversely impact the caregiver’s employment, financial and social situation, and physical and emotional well-being.
• The responsibility falls disproportionately upon women.
• Caregivers benefit from supportive and flexible employment policies, culturally appropriate services, social support and financial assistance.

What this paper adds
• Most respondents were concerned about inadequate/uncertain income (90%) followed by social (77%), physical (63%) and emotional (57%) consequences.
• While nearly half were still working, 28% had their jobs terminated or had quit due to care-giving responsibilities.
• Almost half complained of fatigue and a third, feelings of depression. Two-thirds or more would welcome recognition and understanding from the community.

Abstract
This article presents the findings of a self-report study of the consequences of being an informal caregiver in Malaysia. The aim of this exploratory study was to examine Malaysian efforts in assisting informal caregivers, based on an analysis of the issues and concerns raised by the caregivers themselves. Data were obtained from a cross-sectional survey of informal caregivers in 2009. This sample comprised parents, spouses and/or adult siblings, and adult children, caring for their children, spouses or siblings and parents who were chronically ill and/or had a disability. Of 300 prospective participants, only 175 could be located (58%), but all those contacted agreed to participate. Respondents were randomly selected and interviewed using a structured questionnaire to identify the emotional, financial, social and physical issues consequent upon being a caregiver. Most respondents reported that their care-giving responsibilities had impacted their emotional, financial, social and/or physical well-being. Inadequate and/or uncertain income was by far the greatest concern followed in descending order by social, physical and emotional consequences. The one-way analysis of variance showed significant differences among the three categories of caregivers with respect to physical and emotional consequences. The findings show that care-giving has detrimental effects on the lives of informal caregivers, and that they are in significant need of social support to help them deal with care-giving tasks and responsibilities. Based on the findings, an integrated social support programme is proposed, tailored to the needs of informal caregivers.

Keywords: chronically ill, family caregivers, informal caregivers, Malaysia, social supports

Introduction
This paper considers the consequences of being an informal caregiver in the urbanised, socially and economically dynamic, and pluralistic society of Malaysia. Social care, and especially informal care, has become a critical issue in Malaysia. The paper highlights the unfavourable consequences of care-giving among a sample of informal caregivers and documents their needs for social support. We first describe the situation in Malaysia with respect to informal care. We then outline the study methodology and findings. We conclude with suggestions for an evidence-based social support programme for informal caregivers.

Community care in Malaysia refers to the web of care and support provided to frail, sick or dependent persons with a disability by their
services has been increasing as the government has depended upon public sector care. The cost of careous years has resulted in a growing populationprivate market. Poor economic performance in previ-slowly being replaced by a care system based in the

privileged. for the majority of Malaysians, especially the less
dised by the government, which provides a safety net
care in Malaysia are national and heavily subsi-dised social care. Eligibility rules have been tight-

in terms of resources and supports for informal caregivers (Ong 2009). Most informal caregivers in

Informal care refers to care provided by family, friends and neighbours, and to those who receive such care (Ungerson 1995, Siti Hajar 2007, Spicker 2008). Rooted in attachment based on emotional involvement, it is provided without monetary compensation by members of one’s social network who have had no special training (Walker et al. 1995, Alcock et al. 2002).

Family care-giving is a strong Malaysian tradition. Social values such as filial piety and the obligation to ensure family members’ well-being are carried out with devotion among most Malaysians. Religious teachings (Islam, Christianity, Hinduism and Confucianism) motivate most Malaysians to be compassionate and responsible for the welfare of others, especially family members. However, social changes have eroded the family’s ability to carry out its traditional care-giving functions effectively. Families have had to accept the fact that they need support from other social entities in performing care-giving tasks. Social care has therefore become more of a public policy issue.

Recent years have seen an increase in informal care in Malaysia due to a growing aged population (Ong 2009), an increasing incidence of chronic and degenerative diseases (i.e. diabetes, hypertension, cardiovascular illness, stroke) (Phua 2009), and an increasing number of road and workplace accidents. While Malaysia has multiple tiers of care, the public sector remains the exclusive source of care for 80% of Malaysians (Chee & Barraclough 2009). Most social services in Malaysia are national and heavily subsidised by the government, which provides a safety net for the majority of Malaysians, especially the less privileged.

Since the 1980s, with the adoption of the Privatization Policy, public care financed through taxation is slowly being replaced by a care system based in the private market. Poor economic performance in previous years has resulted in a growing population dependent upon public sector care. The cost of care services has been increasing as the government has sought to reduce the state role in financing, delivering and managing public sector care. As shown by the experience of Britain, a reduction in public care is associated with an increased reliance on informal care (Pickard 2012), thereby shifting a portion of the care burden and expense from public entities to private individuals.

In Malaysia, rural to urban migration resulting from rapid industrialisation has had a major impact on the social structure, norms and values of the society. New work patterns have led to a change in family structure and patterns of interaction (Fatimah 2004). The growing prevalence of the nuclear family and separation from extended family relations, smaller household/family size (from 5.22 in 1980 to 4.31 in 2010), the participation of women in the labour force, increasing age at marriage and the longer life-span have put many urban families in a difficult situation in terms of providing care for family members (Fatimah 2004). Those who can afford it hire domestic help, mostly foreign workers. There are about 224,544 domestic workers in Malaysia, mainly from Indonesia, the Philippines and Cambodia (The New Straits Times 2012). Despite the growing number of paid domestic workers, the need for unpaid informal caregivers is substantial and growing.

Government policy has sought to find ways to support informal caregivers through initiatives such as the Community Care Policy 1990, which has been updated in the National Social Policy 2003 (Ministry of Women, Family & Community Development, Malaysia 2003). This policy recognises the importance of informal care as one of the assumed sources of long-term care along with institutional care for the chronically ill. Objective three of the Policy sets forth the government commitment to develop an integrated social support system and social services for informal care and for caregivers. At the same time, the welfare system in Malaysia has undergone significant reductions in state-subsidised social care. Eligibility rules have been tightened; and those who cannot afford to pay for formal care have to depend on informal caregivers for further rehabilitation. With the shift from institutional care to community-based care, most social services, and especially welfare services, are increasingly tailored to community-based care. These circumstances are similar to those in the UK and elsewhere (Manthorpe et al. 2010).

Many studies have confirmed that care-giving is demanding, laborious and stressful. It has significant consequences for all aspects of caregivers’ lives (Andersson et al. 2002, Gibson et al. 2003). In Malaysia, recognition of the need for research on informal
care is fairly recent. Wan et al. (2003) studied social support and burden among 70 caregivers of patients with dementia in Malaysia; they found that informal support was significantly associated with a lower burden perceived by the caregivers. However, formal support such as assistance from maids and private nurses did not alleviate caregivers’ perceived burdens. Chinese caregivers experienced a higher level of burden as compared with Indians and Malays. Fatimah et al. (2008) examined families’ care-giving to persons with schizophrenia in Malaysia. These caregivers coped with a wide range of mental, financial, physical and social problems. Most reported serious problems of social isolation. Osman et al. (2010), in their cross-sectional study of caregivers of schizophrenic patients at a public hospital in Malaysia, found that caregivers experienced emotional distress, frustration and burnout. This had a significant disruptive effect on family functioning, especially on communication and family roles. These Malaysian studies replicate findings from developed countries showing that informal caregivers need support from other social care sectors.

Methods

The aim of the study was to identify the consequences of care-giving responsibilities and to recommend an appropriate social support programme for informal caregivers based on an assessment of the caregivers’ needs. A self-report methodology was used as it permits respondents to describe an aspect of their life experience (Hagan 2001), and give their views about a particular topic (McLaughlin & Muncie 2001). This method is well suited to capturing experiences from the respondent’s perspective and to identifying the personal and social factors related to the situations under study.

We developed a structured questionnaire, the Social Support Needs Amongst Informal Caregivers 2009. Section 1 of the questionnaire asked about the care recipients’ situation, such as type of sickness/disease, treatment they are receiving and any cash assistance they receive for the cost of treatment. Section 2 was about the social, physical, emotional and financial consequences of being caregivers. The questions about the consequences of care-giving were grouped into four components: financial (nine items), social (nine items), physical (three items) and emotional (six items). For example, respondents were asked if they agree/disagree with statements such as ‘my monthly income is inadequate and I am in financial strain’, ‘I have to change my daily routine’ and ‘I feel like I am “being put away” from others’. These items were adapted from two standardised instruments: the Zarit Burden Interview (Zarit et al. 1986) and the Caregiver Strain Index (Robinson 1983).

The first part of Section 3 consisted of questions on the sources of assistance for the caregivers in times of need, such as ‘aid from a related agency to solve the problem’. Items for this section were adapted from the Social Support Questionnaire Short Form by Sarason et al. (1987). The second part of Section 3 concerned the kinds of social support needed by informal caregivers. Respondents were asked to identify types of support they required, as for example, ‘I need a person who can inspire me and boost my spirits’. These items were adapted from the Berlin Social Support Scales by Schwartzer and Schulz (2003) and UCLA Social Support Inventory by Dunkel-Schetter et al. (1986). Section 4 asked about household composition and the caregivers’ education, employment status and income.

The questionnaire was translated by one of the authors into Malay, the national language. Questionnaires were administered in face-to-face interviews conducted by University of Malaya students enrolled in the course Social Work with Families, who received training for this task. A pilot test was conducted to assess the instrument’s suitability to the local social context. As the questions were found to be well accepted and understood, no changes were made in the questionnaire.

The framework for obtaining ethical approval did not exist in Malaysia at the time of this study, but we endeavoured to safeguard participants as would be required by a formal ethics committee. Before administering the questionnaires, the interviewers explained the purpose of the study, its confidentiality, potential risks and benefits, and that the caregivers had the option to decline to participate without any consequences. They obtained the respondents’ verbal consent to proceed. None of the prospective respondents whom we contacted declined to participate.

The sample comprised persons providing care for members of their family chronically ill and with a disability who were co-residing with the care recipients. It was drawn from caregivers residing in the Kuala Lumpur Federal Territory and the state of Selangor, both of which are heavily urbanised and industrialised, ethnically diverse, roughly approximating the population of Malaysia. For the purpose of research administration, Kuala Lumpur and Selangor were divided into three parts: Petaling Jaya and Puchong; Cheras and city centre of Kuala Lumpur; and Selangor, Batu Caves and Gombak. Due to financial constraints, we were unable to include respondents from rural areas.
We used two sampling techniques. In the first stage, purposive sampling was used to obtain contact addresses for three groups of care recipients: chronically ill children, aged persons and non-aged adults with a disability. For the aged group, we obtained a list of 385 old age assistance recipients from the Malaysia Welfare Department of Kuala Lumpur and Selangor. These aged persons who receive this monthly cash and in-kind assistance are seriously ill or with a disability. For the adult group with a disability, we drew upon the Social Security Organisation list of 246 recipients of Permanent Disability Allowance, who have 80% or more permanent impairment due to occupational injury or accidents while at work. The Medical Social Work Unit at the University Malaya Medical Centre provided lists of 222 parents whose children were chronically ill outpatients. In the second stage, we randomly sampled 100 potential participants from each list (caring for an aged person, an adult with a disability and a chronically ill child). The decision to limit each category to 100 was dictated in part by resource constraints. This procedure was carried out by a team of six enumerators under the supervision of one of the authors.

We analysed overall scores and individual items for our questionnaire using SPSS version 17 (IBM, New York, NY, USA). A one-way analysis of variance (ANOVA) was applied to compare the mean number of consequences per participant across the three categories of caregivers. Pearson’s chi-square test was used to compare the three groups of caregivers by gender, and Fisher’s exact test was used to compare the three groups of caregivers by ethnicity and employment status.

Results

We located 175 (58%) of the 300 prospective respondents: 80 (21%) of the 365 on the aged list, 47 (19%) of the 246 on the list of adults with a disability and 48 (22%) of the 222 on the children’s list. The remaining 125 (42%) could not be found, due to incorrect or inaccessible addresses, or their having moved. Several had no caregivers, and several had died, but we did not record this information.

As shown in Table 1, the care-giving burden was carried disproportionately by women; 74% of the respondents were female and 26% male, the difference being statistically significant (P < 0.001). Women comprised 92% of those caring for children, 72% of those caring for aged people and 60% of those caring for adults with a disability. Almost half the participants (46%) were caring for an aged person, while 27% were caring for an adult with a disability and 27% for a child. Those caring for an adult had a mean age of 62.8; those caring for an aged person or child

<table>
<thead>
<tr>
<th>Table 1 Respondent profiles</th>
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</thead>
<tbody>
<tr>
<td>N (%)</td>
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<tr>
<td>N (%)</td>
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<td>Age</td>
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<tr>
<td>n (%)</td>
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<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
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<td>Ethnicity</td>
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<tr>
<td>Malay</td>
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<tr>
<td>Chinese</td>
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<tr>
<td>Indian</td>
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<tr>
<td>Others</td>
</tr>
<tr>
<td>Employment status</td>
</tr>
<tr>
<td>Unemployed</td>
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<tr>
<td>Self-employed</td>
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<tr>
<td>Private sector worker</td>
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<tr>
<td>Civil servant</td>
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<tr>
<td>Part-time worker</td>
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</table>
were much younger, with mean ages of 36.6 and 35.9 respectively. One-way ANOVA showed the differences to be statistically significant ($P < 0.001$). Sixty per cent were Malay, 31% were Indian, 8% were Chinese and 1% was from other ethnicities. By comparison, the overall population of Malaysia is 27 million of which Malays comprise 67%; Indians (mostly Tamil) 8%; Chinese, 24%; and indigenous and other ethnic groups, 1% (Department of Statistics & Economic Planning Unit 2010). Thus, the participation of Chinese caregivers was quite low relative to their number in the population, while the number of Indians was much higher. Fifty-three per cent of the respondents reported being unemployed, 24% were self-employed, 5% worked in the public sector, 15% worked in the private sector and 3% reported having part-time jobs. Of those caring for an adult with a disability, 70% reported being unemployed, while 52% of those caring for a child and 43% of those caring for an aged person were unemployed. The statistical analysis showed that there were significant differences in employment status among the three groups of caregivers ($P = 0.007$). This disparity most likely reflects the fact that the caregivers of the adults with a disability were much older, with a mean age (62.8), an age at which many voluntarily leave the labour force.

Most respondents reported that their care-giving responsibilities had impacted their emotional, financial, social and/or physical well-being (Table 2). Inadequate and/or uncertain income was by far the greatest concern (reported by 90% of the participants), followed in descending order by social (77%), physical (63%) and emotional consequences (57%). One-way ANOVA showed significant differences among the three categories of caregivers with respect to physical and emotional consequences. Posthoc tests showed that those caring for an adult with a disability reported significantly fewer physical consequences than those caring for aged persons or children; and those caring for children reported fewer emotional consequences than those caring for aged persons or adults with a disability. However, one-way ANOVA showed no significant differences among the three categories of caregivers with respect to financial and social consequences.

### Consequences for respondents’ financial situation

Being a caregiver negatively impacted participants’ financial situations both directly and indirectly through the need for increased household expenditures (Table 3). About three-fourths reported experiencing financial strain due to inadequate income. For most (81%), the high cost of medical treatment and medications for sick family members strained the household budget. The care-giving consequences on employment are also shown in Table 3. Altogether, 28% reported having been terminated (10%) or having had to quit their jobs (18%) due to their care-giving responsibilities. More than a quarter (30%) had had to seek extra work to generate additional income, while 27% reported that their work performance had suffered due to their care-giving responsibilities.

### Care-giving consequences for respondents’ social lives

Social strains were the second most frequently mentioned concern reported by the respondents. A total of 77% (see Table 2) reported that care-giving responsibilities took up much of their time, limiting their

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**Table 2** How does care-giving impact your life?

<table>
<thead>
<tr>
<th>Types of care-giving consequences</th>
<th>Financial n (%)</th>
<th>Social n (%)</th>
<th>Physical n (%)</th>
<th>Emotional n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents who are caring for an aged person ($n = 80$)</td>
<td>68 (85)</td>
<td>63 (79)</td>
<td>58 (73)</td>
<td>53 (66)</td>
</tr>
<tr>
<td>Respondents who are caring for an adult with a disability ($n = 47$)</td>
<td>41 (87)</td>
<td>32 (68)</td>
<td>30 (4)</td>
<td>30 (64)</td>
</tr>
<tr>
<td>Respondents who are caring for a child ($n = 48$)</td>
<td>48 (100)</td>
<td>39 (81)</td>
<td>23 (48)</td>
<td>16 (33)</td>
</tr>
<tr>
<td>Total</td>
<td>157 (90)</td>
<td>134 (77)</td>
<td>111 (63)</td>
<td>99 (57)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents who are caring for an aged person ($n = 80$)</td>
<td>3.3 (2.5)</td>
<td>3.6 (2.8)</td>
<td>1.9 (1.5)</td>
</tr>
<tr>
<td>Respondents who are caring for an adult with a disability ($n = 47$)</td>
<td>2.5 (1.9)</td>
<td>3.3 (2.8)</td>
<td>1.8 (1.6)</td>
</tr>
<tr>
<td>Respondents who are caring for a child ($n = 48$)</td>
<td>3.4 (1.5)</td>
<td>3.3 (2.4)</td>
<td>1.2 (1.5)</td>
</tr>
<tr>
<td>One-way analysis of variance</td>
<td>$F = 2.58$</td>
<td>$F = 0.24$</td>
<td>$F = 3.38$</td>
</tr>
<tr>
<td>df</td>
<td>2, 172</td>
<td>2, 172</td>
<td>2, 172</td>
</tr>
<tr>
<td>$P$</td>
<td>0.079</td>
<td>0.784</td>
<td>0.036</td>
</tr>
</tbody>
</table>

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leisure and/or recreational time with other family members and friends. Ways in which being a caregiver affects respondents’ social lives are summarised in Table 3. Nearly half reported having little free time for themselves (46%) or for leisure activities (47%). Sixty-six per cent had to adjust their domestic tasks as well as change their daily routine. While 43% faced limitations in their ability to leave the house due to their care-giving responsibilities, 39% reported their social life had suffered. On the other hand, most appeared to be coping with and adjusting to their circumstances. Only 19% of the respondents agreed with the statement, ‘my life is a mess and in chaos’ and a relatively low 14% reported that their care-giving had affected their relationships with other family members.

Physical consequences of care-giving

Care-giving tasks such as bathing, feeding, changing care recipients’ clothes and bedding are physically demanding. As shown in Table 3, nearly half (48%) reported being chronically tired, with 41% reporting that their sleep was disturbed. One-third suffered health effects such as loss of appetite and weight loss, or headaches. The majority, however, reported no such ill effects.

Care-giving consequences for respondents’ emotional well-being

Relatively few respondents reported serious emotional ill effects as a result of their care-giving respon-
sibilities. While close to half (47%) complained of fatigue, and a third, feelings of depression, only 14% reported feelings of anger and 17% being disappointed with their lives.

**Social support and assistance needs**

In addition to identifying the consequences of giving care to their family members, we asked our respondents what could help them alleviate their care-giving burden, and what kinds of support they would wish to have (Table 4). The vast majority (95%) identified financial help with medical costs as needed. Information and help in solving specific care-giving concerns was identified by 78% of the respondents. Somewhat fewer (51% and 58% respectively) identified professional counselling and advice from others with similar caretaking issues as a needed kind of assistance.

The caregivers were also asked about their expectations from community members (Table 5). The responses showed broad agreement with the need for various kinds of social support. No fewer than 65% answered affirmatively for each item in this section, so most respondents would welcome recognition and respect, support and encouragement, appreciation and understanding from the community.

**Discussion**

As shown in this study, the provision of care within households profoundly affects the employment experience, earnings and income of the caregivers. While some caregivers managed to combine care-giving with paid employment, many needed to be full-time caregivers. For those who work, many struggle to fit their care-giving responsibilities within their working life pattern. Caregivers who are working have to juggle between a job and care-giving (Fast et al. 1999, Andersson et al. 2002, Bullock et al. 2003, Guberman et al. 2012). Many end up with part-time work that offers much less in income, security and advancement. Others give up employment altogether to undertake full-time care-giving. Studies, ours included, have shown how being a caregiver can prevent one from seeking or accepting a permanent job, forcing one to work fewer hours and/or undergo forced retirement from the labour force (Evandrou & Winter 1989, Parker & Lawton 1994, Arber & Ginn 1995, Humble et al. 2012). Their commitment to care-giving tasks may negatively affect their job performance and reduce their chances of promotion too. Besides affecting the caregivers’ career prospects, it also has dramatic consequences on the financial situation of the co-resident caregivers’ households. With reduced earnings, and with the additional costs incurred from care-giving (Baldwin & Parker 1991), many become reliant on government support, which only partially helps to reduce the caregivers’ burden (Evandrou & Winter 1989).

Evidence from other countries shows that workplace support and flexible employment policies for informal caregivers can be positive and practical (Corti & Dex 1995, Gordon et al. 2012). Such measures 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 (Glendinning 1992, Gordon et al. 2012).

### Table 5 What do you expect from your community members? 
(N = 175)

<table>
<thead>
<tr>
<th>Item</th>
<th>1</th>
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<th>3</th>
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<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
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<tbody>
<tr>
<td>I need this from my community</td>
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<tr>
<td>Persons who can give support and encouragement</td>
<td>171 (98)</td>
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<tr>
<td>Persons who can respect me and what I am doing</td>
<td>165 (94)</td>
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<td>Persons who can understand me</td>
<td>162 (93)</td>
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<td>Persons who appreciate my sacrifice and responsibility to take care of sick family member</td>
<td>157 (90)</td>
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<td>Persons who care for my well-being</td>
<td>155 (89)</td>
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<td>Persons who offer to help me in giving care to my sick family member</td>
<td>151 (86)</td>
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<td>Persons who can listen to my problems</td>
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<td>Persons who can inspire me and boost my spirits</td>
<td>149 (85)</td>
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<tr>
<td>Persons who are calm</td>
<td>141 (81)</td>
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<tr>
<td>Persons who can cherish me or make my life happy</td>
<td>138 (79)</td>
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<tr>
<td>Person who can give advice before I need to make important decisions</td>
<td>132 (75)</td>
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*Note: The table shows the number of respondents who answered ‘Yes’ for each item.*
Being an informal caregiver has significant consequences for one’s mental health. Most studies in the literature as well as several local studies (Wan et al. 2003, Fatimah et al. 2008, Osman et al. 2010) found that many caregivers experienced severe mental health problems associated with their care-giving roles. As reported in the literature, most informal caregivers feel angry, tired, depressed, and uncertain with their care-giving role and tasks, feel ‘suffocated’ and frustrated with their lives (Fast et al. 1999, Andersson et al. 2002). In contrast to these findings, the caregivers in our study appeared more accepting of their situation. While a third did report feelings of depression, relatively few reported being angry (14%) or disappointed with their lives (17%).

Caregivers need services tailored to their individual circumstances, and provided with sensitivity. In our study, those caring for an aged person, an adult with a disability and chronically ill child differed in gender, age, ethnicity and employment status. Caregivers and care recipients of different ethnic and religious backgrounds require services in keeping with their traditions and beliefs (Wan et al. 2003). Studies of social care in England and Wales (Young et al. 2006, Manthorpe et al. 2009), the US (Lee & Yim 2013) and Germany, Italy and Spain (Kluzer et al. 2010) show how ethnicity and religious teachings influence care-giving activities. In a pluralistic society like Malaysia, each ethnic group’s cultural and religious beliefs and traditions provide unique strengths as well as constraints in implementing social care. At present, such limited services that do exist are provided by private, non-profit agencies and charitable groups and are organised based on caregivers’ ethnicity and religion and do accordingly offer culturally appropriate services for the specific groups they serve. However, an integrated social support programme for informal caregivers has yet to be implemented in Malaysia.

Irrespective of cultural differences, caregivers need opportunities for a break, practical help, someone to talk to about their own emotional needs and information about benefits and services (Chow & Ho 2012, Greenfield et al. 2012, Robinson et al. 2012, Green & Gray 2013). In Malaysia, especially in urban areas, those needs are hard to meet. Most adult women now participate in the formal labour force, and most families live in housing estates far from their extended families. Those who can afford it hire foreign domestic workers, while the rest juggle domestic chores, paid work and care-giving. Help from neighbours varies according to social class. Working-class families who live in squatters’ areas near Kuala Lumpur normally help their neighbours by providing meals and looking after children when their neighbours are sick or hospitalised (Azizah 1986). For middle class families residing in housing estates near Kuala Lumpur, social support is derived through social networks established during university days and through professional or job-related connections as well as family and kinship networks. They also rely on foreign domestic help (Fatimah 1994).

Malaysia lacks sufficient services and expertise for providing integrated social care to support informal caregivers. Basic care services such as help with daily living, mobility, self-care and day care are scarce in both public and private sectors. It was only in 2000 that the Central Welfare Council of Peninsular Malaysia introduced a voluntary home visiting service, the Home Help Service, to provide support to the elderly people and their caregivers. These services are mainly offered by unpaid volunteers through non-profit NGOs and voluntary organisations. The services are limited to elderly persons and their caregivers, and do not cover caregivers for other groups of dependants.

Unlike caregivers in the UK, where rights and needs are safeguarded through the Carers Act of 1995, caregivers in Malaysia are not provided with any legal framework governing their participation in the social care system. Caregivers must rely on advocates and lobby groups to campaign on their behalf. In the UK, services addressing the needs of informal caregivers have been advanced through the active advocacy of groups such as the Alzheimer Society and the Gay and Lesbian Network (Manthorpe & Price 2006). In Malaysia, the development of advocacy and lobby groups representing the demands of informal caregivers is much more limited. Such advocacy groups that exist represent only the narrow concerns of specific social groups. What is needed is an overarching advocacy group representing the broad cross-section of caregivers, aggressively campaigning for an agenda supporting all categories of informal caregivers. There is much work to be performed to make the needs of informal caregivers visible to the public and policy makers alike.

Malaysia’s Community Care Policy of 1990, based in part on a policy of the same name in the UK, recognised informal care as one of the major sources of long-term care, together with institutional care for the chronically ill. The policy proposed a set of arrangements, known as ‘care by community to community’, to ensure that informal caregivers, family, friends or neighbours, partner with public agencies to form a network of home and community-based care. This has not, however, been implemented due to lack of public funding and public and political will. What
such a continuum of support services might look like is suggested by the example of the services established in the UK by local voluntary agencies and self-help organisations, often working collaboratively with government agencies. Such services typically include sitting services, respite care, relief care schemes, good neighbour programmes, day centres, day clubs, host family schemes and much more. Also important are social assistance for low-income family caregivers, home health aids, visiting nurses and home care providers who can help with physically challenging tasks as well as offering support to the caregivers.

The UK has established and funded voluntary organisations to provide a range of support services for informal caregivers. An evaluation of a demonstration, the Informal Carers Project, conducted by the Tavistock Institute, found that 43 new services were developed by agencies, from large professional voluntary organisations to small self-help groups of caregivers (Manthorpe et al. 2010).

Despite the formidable stresses, most of our respondents seemed reconciled to being caregivers, a finding at variance with studies in Western countries. Relatively few reported experiencing exhaustion, loss of privacy, fear, embarrassment, anxiety, grief, daily irritation, loss of freedom, social isolation, worry or guilt. Sixty per cent of the study respondents were Malays, who are Muslims. Their acceptance of their care-giving role and its attendant stresses is in keeping with the Muslims’ doctrine of Faith in Predestination (Qada Wa Qadar). It calls upon Muslims to be content and satisfied, even in the face of hardship and adversity. According to the doctrine, Allah has measured out the span of every person’s life and their good or ill fortune. Hence, believers must accept the decree of their God.

Irrespective of one’s beliefs, caregivers face formidable challenges. Barusch (1991) referred to caregivers as the ‘hidden patients’. Services are needed to maintain the health and quality of life of caregivers and to prevent the development of a second patient who herself needs a caregiver (Gaynor 1990, Katbamna et al. 2004, Jeon et al. 2005). Lack of support can seriously undermine informal caregivers’ ability to provide care.

A mixed economy of care policies to support informal caregivers has not yet been fully implemented in Malaysia. The government, through the Ministry of Women, Family and Community Development, is indirectly supporting some efforts to develop social support programmes. In the 2011 National Budget, MYR 70 million (EUR 17.7 million, $22.5 million) was allocated for supporting NGOs to address various social ills. There is, however, no systematic plan for prioritising how the funds are to be distributed. Consequently, priority is given to those dramatic issues receiving media attention such as baby dumping, family/domestic abuse, child abuse and HIV/AIDS rather than social support needs for informal caregivers. Most regrettably, it may take some dramatic and tragic incidents involving informal caregivers to capture public attention and move the social support needs of caregivers higher up on the national policy agenda.

Some limitations of the study should be noted. As mentioned, the sample differed markedly from the ethnic composition of Malaysia, in that Chinese were underrepresented and Indians overrepresented. This discrepancy resulted from the sampling strategy we used. The sampling frame was drawn from public agencies that are relied upon by the Malay and Indian communities much more heavily than by the Chinese. The Chinese community is relatively more affluent and more likely to secure healthcare from private hospitals, and it is less reliant on public services or public income support. While it would have been preferable to sample from private agencies as well, we were unable to secure access to client information from private agencies. Consequently, the findings of this study should only be generalised to caregivers who rely on public services or income support in the study area. The sample did not include caregivers living in rural areas or outside the vicinity of Kuala Lumpur Federal Territory and Selangor, nor was it representative of all categories of persons in need of care.

Forty-one per cent of the prospective respondents could not be located, and we do not know if the actual respondents differed in systematic ways from those not included in the study. Given the use of a structured questionnaire that did not include any open-ended questions, it is possible that there may have been concerns of respondents other than those specifically addressed in the instrument. The questionnaire did not specifically address gradual onset disabilities such as shoulder and back injuries that caregivers often experience as a result of their lifting and moving physically persons with a disability in their care. Respite care was not included as one of the kinds of support respondents could identify as needed (Tables 4 and 5). Another significant omission was the failure to include questionnaire items that reflected potential care-giving benefits and positive consequences.

**Conclusion**

Care-giving can no longer be considered a private family matter between the caregiver and care recipient.
It potentially involves multiple social networks including extended family, community members, state and voluntary sectors sharing responsibilities for providing care. In Malaysia, modernisation has brought impressive gains in living standards. It has, however, also brought increases in disability and chronic illness associated with rising affluence, while eroding traditional family support networks. Policy pronouncements alone are not sufficient. Care-giving, formal and informal, merits a much greater share of governmental resources consistent with Malaysia’s impressive modernisation project.

References


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