Coping Strategies Among Mothers of Chronically Ill Children: A Case Study in Malaysia

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Published online: 05 Feb 2014.

To cite this article: M. A. Nur Saadah, A. B. Siti Hajar & M. Rezaul Islam, Journal of Social Service Research (2014): Coping Strategies Among Mothers of Chronically Ill Children: A Case Study in Malaysia, Journal of Social Service Research, DOI: 10.1080/01488376.2013.866613

To link to this article: http://dx.doi.org/10.1080/01488376.2013.866613

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Coping Strategies Among Mothers of Chronically Ill Children: A Case Study in Malaysia

Nur Saadah M. A.
Siti Hajar A. B.
M. Rezaul Islam

ABSTRACT. The purpose of this study is to identify the stresses and coping strategies of five mothers in caring for their chronically ill and disabled children. These mothers were receiving services from a nonprofit hospital in Malaysia. Through an in-depth case study design, the findings indicated that emotional stress caused high levels of depression, which decreased life satisfaction that led to poorer physical health. Issues explored included employment, noncooperation of family members, as well as factors related to the mother's individual abilities and how these factors might affect maternal caregiving. Recommendations for future research include identifying probable psychosocial stresses and other associated factors while emphasizing the importance of community-based programs that minimize these stresses.

KEYWORDS. Informal caregiving, maternal bonding, children with disabilities, stress, coping strategies, social supports, Malaysia

INTRODUCTION

The birth of a child with a disability, whether the disability is physical or mental, can affect all family members as well as all internal and external relationships (Taanila, Syrjälä, Kokkonen, & Jarvelin, 2002). The literature shows that the caregiving coping strategy exhibited by the mother can differ based on her socioeconomical and psychological conditions. However, coping with chronically ill children is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event. In terms of physical consequence, caregiving tasks are difficult. Caregiving for a child with special needs can be difficult and may require repeated lifting and transferring of the child to assist with bathing and toileting, changing diapers and clothes, and cleaning their bed. These tasks may be so burdensome that many caregivers complain about their own physical health deterioration caused by the caregiving
tasks that must be provided to ensure a healthy environment for their child (Cheung & Hocking, 2004; Earle & Heymann, 2011; Houtven, Voils, & Weinbeger, 2011; Mehta, 2005). Problematic health conditions experienced by caregivers include stroke and a lack of support leading to the failure to achieve proper rest. Others have voiced concerns related to financial distress (Kerr & Smith, 2001; Smith et al., 2004). Constant demands on their time related to caregiving can force many caregivers to give up their formal or full-time employment, which can lead to severe economic hardship (Bittman, Hill, & Thomson, 2007; Carmichael & Charles, 2003). This is especially problematic when the caregiver is also the sole breadwinner for the family.

The third National Health Morbidity Survey conducted in 2006 provided a nationally representative sample of the population in Malaysia related to the prevalence of chronic illness. Of the 57,500 eligible respondents, 56,710 (98.6%) of whom participated in the study, it was estimated that the overall prevalence of chronic illness within a recall period of 1 year was 15.5% (95% CI [15.1, 15.9]). Incidents of chronic illness were reported as significantly higher among women (16.8%, 95% CI [16.3, 17.3]), with the most common chronic illness noted being hypertension (7.9%, 95% CI [7.6, 8.2]), followed by diabetes mellitus (4.0%, 95% CI [3.8, 4.2]; Amal, Parameswarathy, Tee, Gurpreet, & Karuthan, 2011). Although data are limited regarding the prevalence of chronic illness among children in Malaysia, it was previously estimated that the prevalence among children younger than 18 years of age is 10% to 30% (Newacheck, 1994). The estimates vary due to differences in the survey methods used (definition and measures), sample location and characteristics, and timing of the studies (Hobbs, Perrin, & Ireys, 1985). According to Ahmed (2008), the total death count in Malaysia was 119,000 in 2002; the chronic disease-related death count was 85,000, which accounted for 71% of deaths. Boey and Goh (2001) looked at the link between childhood recurrent abdominal pain (RAP) and the presence of recent life events in an urban community in Malaysia among school children aged 9 to 15 years old in the area of Petaling Jaya in Kuala Lumpur, Malaysia. They found that the prevalence of RAP among 1,488 schoolchildren studied was 9.6%. Therefore, like many other countries, the prevalence of chronic illness among children is a growing concern in Malaysia.

In addition, there is a growing body of theoretical and practical findings related to the impact of stresses and coping strategies parents faced in providing services for their chronically ill and disabled children. In Malaysia, however, this research is more limited. Noralina, Nur Saadah, Siti Hajar, and Fatimah (2010), Othman (2004), and Ong, Chandran, and Peng (1999) covered some components of informal caregiving experiences of chronically ill and disabled children in Malaysia. For example, Othman examined the role of parental overprotection and disease-related variables in exacerbating psychological problems of children suffering from chronic illness. The results from 63 parents of children suffering from cancer, epilepsy, and asthma revealed that children with cancer showed more aggressive behaviors than did epileptic and asthmatic children, while epileptic children faced greater social problems than did children with cancer and asthma. Ong et al. examined parenting stress among Malaysian mothers who had a child diagnosed with mental retardation and found a large proportion of these mothers experienced substantial parenting stress, especially unemployed mothers who were of Chinese descent. Another need for these children is long-term care because for most families, all services were provided at home with the mother being expected to take full responsibility for meeting the needs of the child.

Many of these mothers voice concerns related to increased mental stress (Beckman, 1991; Tak, 1994), and they worry they will not be able to meet the needs of the child and overcome the burden without outside help (Dwyer & Miller, 1990; Lazarus & Folkman, 1984; Ogden, 2007; Patterson, 1988). For example, when these mothers are stressed, they are reported to experience neck pain and muscle spasms related to the extreme pressures required of them as a caregiver. Stress can also lead to cognitive function problems and loss of focus with difficulty remembering (Ogden, 2007). These detrimental effects can affect caregiving and result in negative
behavior changes. Mussatto (2006) reported that parents of children with congenital cardiac disease demonstrated undesirable behavior such as anger, despair, and frustration.

The main objective of this case review is twofold. First, it identifies the types of stresses that informal caregiving mothers experience while providing services to their chronically ill and disabled children, and second, it identifies the coping strategies they use. This study seeks to answer the following questions: What types of stresses are the mothers suffering? What are the coping strategies practiced by informal caregivers? And what are effective social support programs for improving their caregiving?

**LITERATURE REVIEW**

**Stress**

Risk factors for stress-related illnesses are a mixture of personal, interpersonal, and social variables. These factors include lack or loss of control over one’s physical environment and lack or loss of social support networks. People who are dependent on others (e.g., children or the elderly) or who are socially disadvantaged (because of race, gender, education level, or similar factors) are at greater risk for developing stress-related illnesses. Other risk factors include feelings of helplessness, hopelessness, extreme fear or anger, and cynicism or distrust of others. Farmer and Lee (2011) found that parenting stress undermines one’s sense of perceived mastery, which, in turn, results in depression. They added that parenting stress directly affected maternal depression and parent–child interaction. Parenting stress has been associated with both the maltreatment of children with disabilities and increased potential to abuse children with disabilities (Anoil, Mullins, Page, Boyd, & Chaney, 2004; Rodriguez & Murphy, 1997). Murray, Fiori-Cowley, Hooper, and Cooper (1996), Kiernan and Huerta (2008), Zarit, Femia, Gatz, and Johansson (1999), and Choi, Stafford, Meininger, Roberts, and Smith (2002) found that parental depression persuades parents to be less sensitive toward their children and use more harsh discipline with their children.

**Informal Care and Informal Caregivers**

Once a child is discharged from the hospital and sent home for rehabilitation, the responsibility of caregiving rests with the parents. In most families, the greatest responsibility for care often rests with the mother. These mothers’ experiences and problems are different due to cultural and economic differences and the health services they receive (Borhani, Asadi, & Mohsenpou, 2012). Family members are required to perform specific duties of care ranging from light assistance with independent activities of daily living, such as accompanying the patient for medical follow-up, to intensive in-home care (Steffen & Mangum, 2005), such as administering personal hygiene activities, dressing, changing clothes, cleaning the patient’s private body parts, and ensuring general safety and well-being (Moonie, Chaloner, Pensley, Stretch, & Webb, 2000).

**Coping Strategies**

Two prominent models, the coping model developed by Lazarus and Folkman (1984) and the resiliency model of family stress, adjustment, and adaptation by McCubbin and McCubbin (1996), are significant coping strategies that parents follow in providing services to their chronically ill and disabled children. The coping model places emphasis more on psychological aspects. This model has two styles: an emotion-focused coping style and problem-focused coping style. Each style has its own strategies. The emotion-focused coping style is defined as an inner coping style, which enforces an individual’s feelings or emotions. It aims to reduce emotional stress. This style has six strategies including social support, self-control, positive reappraisal, accepting responsibilities, escaping/avoidance, and distancing. On the other hand, the problem-focused coping style is an alteration of the stressful situation that aims to solve the problems causing the stress. The resiliency model of family stress, adjustment, and adaptation emphasizes the family environment, either a cause of stress or as facilitating factors to coping strategies. This model stress is important in the family environment because family
is the primary caregiver. The model looks at the strength of family as a primary source of coping. Other than family, the model also recognizes the importance of community either in contributing to stress or coping with stress. The model assumes that stress experienced by individuals is either due to family circumstances or external factors that affect the ability of individuals and families to take care of their ill family members.

A child with a chronic condition can be demanding for all family members, and this intense experience requires parents to adapt (Hentinen & Kyngas, 1992). Parenting a chronically ill child can arouse a variety of feelings, such as guilt, anxiety, shock, denial, anger, confusion, and depression (Hentinen & Kyngas, 1992; Melnyk et al., 2001). According to Tew, Landreth, Joiner, and Solt (2002), parents face two basic issues: learning to deal with their child’s health and coping with the stress. Researchers suggest that parents report more parenting stress, less social support, and increased strain on the role of parenting, and they spend a more significant amount of time on caretaking activities than do parents of healthy children. Because of these kinds of stresses, the parents follow a number of coping strategies. The coping strategies are defined as the active processes and behaviors that the family actually tries to employ to help it to manage, adapt to, or deal with a stressful situation. Coping entails constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are considered as taxing the family’s resources (Lazarus & Folkman, 1984; McCubbin & Patterson, 1982; Patterson, 1988). Studies have shown that parents who have a child with a chronic illness are so involved that they often neglect other members of the family (McCubbin, Cauble, & Patterson, 1982). Parents are often overwhelmed with an incredible sense of not knowing what to do, how to act, or to whom can they turn for advice or information. Such an experience often threatens the family symmetry and places serious strain on the parents’ resources and coping abilities (Rushton, 1990). Parental adaptation to the chronically ill child has a major influence on other family members and their well-being (Hentinen & Kyngas, 1992).

A number of studies have concentrated on the degree to which families with disabled children feel stress, how they manage, what factors support them, and what coping strategies they use (Beckman, 1991; Failla & Jones, 1991; Heaman, 1995; Snowdon, Cameron, & Dunham, 1994). The family research literature includes reports on many measures of family coping (Heaman, 1995; Patterson & McCubbin, 1983; Snowdon et al., 1994). In the global context, there is a wide range of studies on the coping strategies that parents follow with their chronically ill and disabled children. Chronic illness and disability affect all facets of life, including social and family relationships, economic well-being, activities of daily living, and recreational and vocational activities (Falvo, 2005, p. 1). Responsibility and the daily chores of informal caregivers are extensive. They need to attend to the physiological needs of the care recipient such as feeding and nourishing, help them with their personal hygiene such as bathing and toileting, provide and arrange their financial needs, and assist them with their emotional disorder. These activities and tasks are exhausting. These laborious caregiving activities and the limitless responsibilities result in stress among informal caregivers. Their burden or stress is severe if the care recipient is suffering from some type of chronic illness. Their acute dependency on their caregivers, who mostly are their family members, leaves long-term effects on the caregivers’ physical, economic, and emotional conditions (Moonie et al., 2000). Burr and Klein (1994) studied and classified a large number of coping strategies mentioned in the literature, and the authors used this classification as a preliminary framework when studying parental coping strategies (Table 1).

Taanila et al. (2002) interviewed 27 children aged 8 to 10 years old. Of the 27 children, 25 were living with their biological parents, 1 was living with his mother, and 1 lived with her mother and a stepfather. The researchers investigated how the parents reacted to their child’s disability and in what ways it affected the life and functioning of the family, the parental relationship, and the parents’ social life and work and leisure time. They also obtained information on how the families had coped, what kind of life they were living at the moment, and what
coping strategies they had used. The results showed that acceptance, good family cooperation, and social support were related to the coping strategies most frequently used. Half of the families seemed to have found successful ways of coping, whereas another half had major problems. There were five main domains in which the high- and low-coping families differed from each other: parents’ initial experiences, personal characteristics, effects of the child’s disability on family life, acting in everyday life, and social support. Fletcher and Clarke (2003) obtained information about the home health care work that parents complete when their children have been diagnosed with cancer. This study provides information about the coping strategies and barriers that mothers communicated through personal interviews. The researchers specifically examined factors that affect mothers’ abilities to cope after the diagnosis. In this study, the interviews, completed with 25 mothers, revealed that the mothers identified many salient issues, one of which was coping, and factors that affected their ability to cope. The coping subthemes identified included feelings of adversity, anger, and despondency; religion, faith, and God; taking control; gender and marital issues; taking care of self; and positive outlook, facing reality, and normalcy. The research provided mothers with a “voice” by allowing them to express their stories and experiences about having a child with cancer or, more particularly, about salient issues surrounding coping. Koller, Richardson, and Katz (1992) and Gibson (1995) found that coping with a physically or intellectually disabled child is a highly individual process, and there is evidence to suggest that some families may never adjust fully to this event. Soulvie, Desai, White, and Sullivan (2012) examined the existing research on the psychological distress experienced by parents whose young children (aged 0 to 5 years old) had a congenital heart defect. A more detailed understanding of the distress experienced by these parents, including stress associated with the child’s age, the severity of the child’s diagnosis, and parents’ characteristics, is vital, as it would allow for more targeted and individualized support for this population to enhance parental coping strategies and increase the likelihood of more positive parent–child interactions. This review of 25 studies contributed to the parenting stress literature by focusing on parents of young children and categorizing studies by publication characteristics, research methodology,

### TABLE 1. The Conceptual Framework of Coping Strategies

<table>
<thead>
<tr>
<th>Highly Abstract Strategies</th>
<th>Moderately Abstract Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive</strong></td>
<td>Be accepting of the situation and others.</td>
</tr>
<tr>
<td></td>
<td>Gain useful knowledge.</td>
</tr>
<tr>
<td></td>
<td>Change how the situation is viewed or defined (reframe the situation).</td>
</tr>
<tr>
<td><strong>Emotional</strong></td>
<td>Express feelings and affection.</td>
</tr>
<tr>
<td></td>
<td>Avoid or resolve negative feelings and disabling expressions of emotions.</td>
</tr>
<tr>
<td></td>
<td>Be sensitive to others’ emotional needs.</td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td>Increase cohesion (togetherness).</td>
</tr>
<tr>
<td></td>
<td>Increase adaptability.</td>
</tr>
<tr>
<td></td>
<td>Develop increased trust.</td>
</tr>
<tr>
<td></td>
<td>Increase cooperation.</td>
</tr>
<tr>
<td></td>
<td>Increase tolerance of each other.</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>Be open and honest.</td>
</tr>
<tr>
<td></td>
<td>Listen to each other.</td>
</tr>
<tr>
<td></td>
<td>Be sensitive to nonverbal communication.</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td>Seek help and support from others.</td>
</tr>
<tr>
<td></td>
<td>Fulfill expectations in organizations.</td>
</tr>
<tr>
<td><strong>Spiritual</strong></td>
<td>Be more involved in religious activities.</td>
</tr>
<tr>
<td></td>
<td>Increase faith or seek help from God.</td>
</tr>
<tr>
<td><strong>Individual development</strong></td>
<td>Develop autonomy, independence, and self-sufficiency.</td>
</tr>
<tr>
<td></td>
<td>Keep active in hobbies.</td>
</tr>
</tbody>
</table>

and findings. The research clearly demonstrated that parents reported a great deal of stress throughout a continuum in the child’s health care experience.

Based on this literature review, the authors have two main observations. First, there is a lack of studies on informal caregiving experiences in Malaysia. However, it is important to know the present situation of informal caregiving for chronically ill and disabled children in order to formulate better policy. Secondly, it is necessary to know the present situation of the coping strategies that informal caregiving mothers adopt to overcome these stresses. This qualitative study is an attempt to achieve these two aspects. The present study reports the findings from interviewed with five informal caregiving mothers in Kuala Lumpur, Malaysia, who were providing care to their chronically ill and disabled children. This study examined the types of stresses that the mothers experienced and the coping strategies that they adopted. In addition, the authors suggest a number of areas for policy implications.

**METHODOLOGY**

The purpose of the study is to identify the types of stresses experienced and the coping strategies used by mothers who are responsible for providing care to their chronically ill and disabled children. A qualitative case study approach was chosen because this method allowed the authors to systematically document the experiences and highlight individual coping strategies.

**Sample**

Purposive sampling was utilized to identify a sample of five full-time caregiving mothers selected from a hospital in Kuala Lumpur. All of the mothers were considered the primary caregiver for their disabled child. The authors also set up inclusive criteria for sampling, including:

1. The caregiver was the primary caregiver for a chronically ill and disabled child.
2. The caregiver was a family member of the care recipient, regardless of sex, age, and relationship with the patient (i.e., mother, father, brother, sister, grandfather, grandmother, aunt/uncle, cousin, or nephew, etc.).
3. The caregiver lived together with the patient.
4. The caregiver had been giving care to the care recipient for at least 6 weeks after the care recipient was discharged from the hospital.
5. The caregiver has the ability to speak either English or Malay language to facilitate the interview process and data collection.

Five mothers were interviewed in depth and were asked about their relationship with their child as well as the duties they performed. All participants were women consistent with the population as 99% of caregivers from the list provided by the two agencies were women. Predominantly, it is a social norm in most East Asian communities, in particular Malaysian, that the responsibility for caregiving of an ill family member rests with the mother (Fatimah, Saim, Nur Saadah, & Mohamad, 2008). All of the respondents were middle-aged adults ranging in age from 35 to 51 years old. All of the participants had attained a moderate education level, with the highest education level obtained by the respondents being the Malaysian Higher Certificate of Education. Two respondents attained the Malaysian Certificate of Education, one respondent attained the Lower Certificate of Education, and another one only managed to attend primary school (until Standard 6). Table 2 summarizes respondents’ profiles. Four mothers were Muslim and one was Hindu. Their children were aged 8 to 14 years old. The children were suffering from cerebral palsy, leukemia, muscular dystrophy, and epilepsy.

**Instrument and Data Collection**

The design of the interview protocol was inspired by established studies such as those by Rodehaver (2008), Lowit and Teijlingen (2005), and Kerr and Smith (2001). Open-ended interview guidelines were employed. The interview guideline was provided to lead the interview session so that the process could flow smoothly in accordance with the scope of study (Kerr &
TABLE 2. Sociodemographic Profiles of the Respondents

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Gender (F/M)</th>
<th>Age (Years)</th>
<th>Race/Religion</th>
<th>Relationship With Patient</th>
<th>Marital Status</th>
<th>Caregiving Duration</th>
<th>Education Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>First mother</td>
<td>F</td>
<td>51</td>
<td>Malay/Islam</td>
<td>Mother</td>
<td>Single mother</td>
<td>11 years</td>
<td>LCE</td>
</tr>
<tr>
<td>Second mother</td>
<td>F</td>
<td>35</td>
<td>Malay/Islam</td>
<td>Mother</td>
<td>Married</td>
<td>1.5 years</td>
<td>HCE</td>
</tr>
<tr>
<td>Third mother</td>
<td>F</td>
<td>48</td>
<td>Malay/Islam</td>
<td>Mother</td>
<td>Married</td>
<td>10 years</td>
<td>MCE</td>
</tr>
<tr>
<td>Fourth mother</td>
<td>F</td>
<td>42</td>
<td>Indian/Hindu</td>
<td>Mother</td>
<td>Married</td>
<td>14 years</td>
<td>MCE</td>
</tr>
<tr>
<td>Fifth mother</td>
<td>F</td>
<td>44</td>
<td>Malay/Islam</td>
<td>Mother</td>
<td>Married</td>
<td>11 years</td>
<td>Standard 6</td>
</tr>
</tbody>
</table>

Note. HCE = Malaysian Higher Certificate of Education; MCE = Malaysian Certificate of Education; LCE = Lower Certificate of Education.

Smith, 2001). In most cases, questions were open-ended with a number of subquestions, which were substituted for the following three main research questions:

- What types of stresses were the mothers experiencing?
- What are the coping strategies practiced by these mothers when caring for their disabled children?
- What kinds of social support programs were utilized and how did they improve the mothers’ caregiving?

On average, each respondent was interviewed three times, and the interviews took place at the respondent’s home so they would be available to care for their child. Each interview was recorded with a voice recorder and was backed up with field notes. The authors themselves carried out all interviews, as they wanted to have in-depth understanding about the subject under investigation. The duration of each interview was 45 min to 1 hr and 30 min. The data collection process ended when the interview reached its saturation point, or when no new data were found in an interview and/or the respondent kept repeating the same information from previous interviews. The data collection period was 6 months (December 2009–June 2010).

**Procedure**

In regards to the ethical considerations of the study, surprisingly, there was no formal institutional review board available to assess the research proposal at either the service agency or the institution in Malaysia. To ensure ethical treatment of the participants, however, the authors followed the ethical guidelines provided by Miles and Huberman (1994). A guarantee of confidentiality and anonymity of sources was given to the authority of the agency and all the participants. Prior to the interviews, it was confirmed that participation in the interview was the interviewee’s own decision and that the participants were able to decline or withdraw from the study at any time. The purpose of the study was explained to interviewees, and all participants were asked to sign interview consent forms. With the consent of the interviewees, all interviews were recorded using a digital voice recorder, and particular attention was paid to ensuring the interviewees’ anonymity. In general, the participants were very enthusiastic about the research topics and interviews. Procedure notes were generally written immediately after concluding each interview.

**Data Analysis**

For each interview that was conducted, verbatim recordings were transcribed and reviewed within 24 hr to facilitate the analysis process systematically. The authors did not use any software to analyze data because they wanted to fully explore and harvest the experiences informed by the respondents and to explore the information provided. First, open coding was 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 rather than by adhering to a specific theoretical approach or envisioning a specific destination for the coding. Then, selective coding was conducted to systematically analyze the data and identify the most prominent themes. The analysis process was “iterative,” meaning that it entailed going back and...
forth between the coded original data and the issues studied (Chon, 2013; Mason, 2002). When presenting the findings from the data, the authors paid particular attention to choosing and using the quotations that would be most relevant to the specific issues. It was felt that this method would help to convey the richness of information (Chon, 2013). To protect the privacy of the participants, their names were not included in the findings; rather the authors refer to them as first mother, second mother, third mother, fourth mother, and fifth mother.

RESULTS

Types of Stresses Faced by the Mothers

The authors grouped stresses into four types: financial, emotional, environmental, and health. As summarized in Table 3, all respondents experienced financial and emotional stresses. Financial inadequacy was claimed by all respondents of this study. All of the participants reported that their economic difficulties rested with their inability to work full-time related to caregiving and/or their inability to work outside of the home due to caregiving demands. Furthermore, it also was caused by the increasing monthly family expenses due to medical bills for the chronically ill family members. In one of the cases, a respondent reported she had limited income to provide medical treatment for her son who was suffering from leukemia.

Caregiving also causes emotional stress due to the failure to maintain an unwavering marital relationship and/or communication with other family members. Most of the participants expressed concerns about their inability to develop relationships with their spouse and other family members. According to the first mother whose son was diagnosed with cerebral palsy, her emotional stress was endless. She started intensive caregiving for her son upon diagnosis, and the burden continues to increase. She had to quit her job as a cleaner in one of the public universities in order to provide the needed caregiving for her son. All of her time was devoted to caring for her son. This required so much attention her husband stopped contact with her and started to spend most of his time outside with another woman. He never helped in caregiving for his son. Her husband abused her physically and frequently. She claimed that her marital problems further stressed her emotionally. She reported that her husband’s unfaithfulness and continued neglect led to their divorce. She said:

At the first time I knew about his illness, I was shocked! It was difficult to accept at that time. I am thinking what people will say. I feel so shame. Then, I have problems with my husband. Before we were divorced, he did not care about his son. It is worst nowadays. I hate to see him. I was so busy taking care of the child. He, on the other hand, was happy to go out with another woman.

Other problems noted were increased environmental stresses and increased health problems. The community—particularly neighbors and family—affects the caregiver’s level of stress. In the case of the second mother, whose child was diagnosed leukemia, she told the authors how bad it was to live with anxiety, shame, and sorrow due to the lack of understanding and absence of support from her neighbors. In this manner, she had experienced environmental stress in her relations with family and others in her environment. The stress was contributed either by the people surrounding her (i.e., neighbors, friends) who lived in the environment or by the social agencies or institutions (i.e., government agencies, voluntary associations, non-governmental organizations) that exist in the environment. According to the second mother, she felt stressed because her neighbors were skeptical about her. They socially insulted her by gossiping that her son’s illness was caused by her past sinful acts. These neighbors made her life miserable by spreading false stories about her. They did not let their children play with her kids. She reported that she suffered emotionally because of her neighbors’ attitudes. She told us:

The neighbors near here are seeing us with scorn. They say my son is ill because of my prior sins. Who are they to judge me? Are they very good person? They never even come to visit us. They also do not give...
TABLE 3. Types of Stresses Suffered by Mothers

<table>
<thead>
<tr>
<th>Types of Stress</th>
<th>Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Financial</td>
</tr>
<tr>
<td>First mother</td>
<td>✓</td>
</tr>
<tr>
<td>Second mother</td>
<td>✓</td>
</tr>
<tr>
<td>Third mother</td>
<td>✓</td>
</tr>
<tr>
<td>Fourth mother</td>
<td>✓</td>
</tr>
<tr>
<td>Fifth mother</td>
<td></td>
</tr>
</tbody>
</table>

their helping hands to us. I do not ask them to visit us, but my stress would relief if they at least ask and understand our condition.

The third mother, whose child was diagnosed with cerebral palsy, claimed that her health was declining due to stress. She had experienced health problems since a year before (in 2009) because her bones were decomposed. This made it difficult for her to care for her son. Moreover, her son was always asking to sit on her lap. Despite her pain, she would rather do so as long as her son was happy. She told the authors:

He is always asking to sit on my lap. Can you imagine how it is, with my weight of 40 kilograms, and his weight of 30 kilograms? That is why, I always suffer back pain and doctor told me that I suffer of decomposing bones. If his father or other person does this, he will tantrum.

As a summary from this part, the study has concluded that informal caregiving contributed to various dimensions of stresses. As demonstrated in Table 3, types of stresses experienced by informal caregivers in this study were interrelated and contagious. Moves from a psychological type of stress to a socioeconomic type of stress, or from the latter to the former type of stress, were obvious. Yet, the patterns of stress were varied among caregivers. Some of them experienced only a certain type of stress, whereas some of them experienced all types of stress. The ways in which each of the stress affected caregivers’ lives were mixed. While some of them reported that caregiving had seriously influenced their financial situation, a few mentioned that caregiving affected their physical well-being more than their emotional and financial circumstances. In conjunction with the statements, the study also confirmed the fact that stress in informal caregivers could be contributed to various psychosocial factors—in particular, the family, the community, and the self of the caregivers.

Coping Strategies Practiced by Mothers

In terms of ways in which the mothers coped with their stresses, all chose to opt for an emotional-focused coping strategy. They were more likely to react emotionally rather than trying to solve the problems or stresses. There were four types of coping strategies that are grouped under the emotional-focused coping strategy; these include social support, self-control, acceptance responsibility, and positive reappraisal (Table 4). This study showed that all respondents were more comfortable to opt for the social support coping strategy. Compared with the other four mothers, the first mother seemed to cope with the self-control strategy and positive reappraisal.

According to all respondents, they most needed social, emotional, and financial support from their family members, friends, and neighbors. All mothers weighed the importance of family support more than the support of friends and neighbors. They hoped their family members would make an effort to understand their feelings and situations and to lend their hands in helping with caregiving. Family members’ understanding and involvement in caregiving activities and responsibilities helped to relieve...
TABLE 4. Type of Coping Strategies Adopted by Mothers

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Social Support</th>
<th>Self-Control</th>
<th>Responsibility Acceptance</th>
<th>Positive Reappraisal</th>
</tr>
</thead>
<tbody>
<tr>
<td>First mother</td>
<td>√</td>
<td></td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Second mother</td>
<td>√</td>
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<td>Third mother</td>
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<td>Fourth mother</td>
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<tr>
<td>Fifth mother</td>
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</table>

caregivers’ stresses. Here, the authors observed that mothers used family coordination and participation as a strategy for utilizing internal resources. This strategy helped individuals—in particular family members—to adjust to the crisis that occurred in the family. This could be achieved by means of strengthening family cooperation and enhancing mutual understanding among family members, family support, and efforts to stabilize a family’s financial situation.

This study revealed that the main support the mothers needed and expected from their family members was emotional support. Family members could show their support by paying constant visits and communicating with the care recipient. From all mothers’ experiences, the authors concluded that informal caregivers actually needed someone to whom they could express their feelings and on whom they could rely for relief of their emotion. In this regard, the third mother told the authors:

I enjoy being together with friends, neighbors, and others who are willing to listen to my problems—especially with those who are in the same shoe with mine. I am not asking for money, but I am asking for friends where we can share our feelings together. I am asking for emotional support...

Even though all mothers demanded that they needed and appreciated emotional support more than material support, they also needed financial and in-kind assistance for patients’ necessities such as milk, diapers, and medicines. The fourth mother, whose child was diagnosed with muscular dystrophy, for instance, told the authors about her terrible suffering that was related to her financial crisis. She said:

I did not get any financial assistance from the government or other agencies. Patient’s diapers are around RM200 (US$62) per month. Monthly expenses are around RM800 (US$248), which covers house rent, utilities, groceries, and food. My husband’s salary is just RM1,200 (US$373). It is not enough! I really need financial assistance from others as well, especially from the Welfare Department.

The authors observed that the social support coping strategy and self-control coping rested in the mothers’ ability to control her thoughts, emotions, and behavior when under stress. In this study, only one mother, the first mother, practiced this type of coping strategy. During the interviews, the authors observed that she had a passive personality because she did not attempt to make eye contact or look at the authors’ faces during the entire interview. Instead, she loved to stare at the floor. The authors found it difficult to explore her feelings and get sufficient information from her. She responded to questions being asked with simple answers like “no husband” or “no problem” in the first and second interview. She only began to cooperate in the third session. When the authors had the chance to explore her feelings and experiences thoroughly, they realized that she was disappointed with the situation of her son, which contributed to her divorce with her husband. To reduce the emotional stress, she would prefer to control her feelings of sadness and stresses by personally suppressing her feelings. Her coping practiced could be said to be in...
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line with Lazarus and Folkman’s (1984) model, which established the idea that self-control coping intends to reduce the emotional stress suffered by an individual. This mother told us:

When there is a problem, I like to keep it to myself. I did not even tell my children. Prayer makes me calm. I cry every time I pray [began crying, wiped away tears]. What can they help if I tell them my feeling?

This coping strategy helps the individual to solve his/her problem, rather than be emotional to it. One significant finding was that this type of coping was the tendency of caregivers to look to religion and/or social norms to justify the problem. The fifth mother, who was a caregiver to her daughter with epilepsy and cerebral palsy, for instance, told the authors that it was her destiny. As a Muslim, she believes has to accept this destiny. She believed that God would reward her if she managed to fulfill the mandated responsibility. The authors mentioned earlier that four of the mothers were Muslims. Their acceptance of their caregiving roles and its attendant stresses was in compliance with the Muslims’ doctrine of Faith in Predestination. As a Muslim, the fifth mother believed that she should be pleased and satisfied, even in facing hardship and adversity. She added, according to the doctrine, God has measured out the span of people’s life and their good or ill fortune. Hence, believers must accept the decree of their God. She said:

Yes, it is not enough income for my family. But I have to accept it as long as we can get enough food, drink and a house to shelter on. I should thank God for that.

Positive reappraisal, on the other hand, means coping in which one’s emotion is reappraised to deal with the stressful situation and look for the positive side of the situation. Positive reappraisal depends on one’s cognitive ability to think positively. The first mother practiced this type of coping. She said that she would never feel burdened by the caregiving responsibilities. At all times, she was confident in her chores. She added that she needed to be positive and see the challenge as her duty as a mother. She believed that God would compensate her if she accomplished the duty sincerely. Due to her positive thinking, she was observed to be a calm person during all interview sessions. She said:

I am pleased with what’s happening now. I have to be strong and positive for that. I believe everything happened . . . for a reason. As long as my children are with me, that is enough.

DISCUSSION AND IMPLICATIONS

The goal of this qualitative study was to explore the experiences of stresses and coping strategies of the informal caregiving mothers who were providing services for their chronically ill and disabled children. According to the experiences of five mothers obtained by in-depth case study, the authors found that the mothers were suffering mainly four types of stresses such as financial, emotional, environmental, and health. Stress is always referred to as a feeling of worry, burden, and anxiety. This finding is supported by Ogden (2007), Dwyer and Miller (1990), Patterson (1988), and Lazarus and Folkman (1984). Stress among family caregivers can be defined as a problem of finance, emotions, conflict, fatigue of being a caregiver, health status, and family life change (Kosciulek, McCubbin, & McCubbin, 1993; Riper, 2007; Tak & McCubbin, 2002). According to Tak (1994) and Beckman (1991), stress can be grouped into four groups: financial, social stress from the environment, personal, and psychological. The types of stresses experienced by mothers were found to be interrelated and contagious. The authors have analyzed how stress moves from the psychological type of stress to the socioeconomic type of stress or vice versa. The patterns of stress were varied among caregivers as some of them experienced only a certain type of stress and some of them experienced all types of stress. The effects of stress were also found to be mixed. Some mothers reported on their financial situation while some mentioned their physical well-being as more critical than their emotional and financial circumstances.
The authors found that there was diversity in the coping strategies used among the mothers, but that the emotional-focused coping strategy was common. The mothers were more likely to react emotionally rather than try to solve the problems or stresses. The nature of such a finding can be compared with the coping model of Lazarus and Folkman (1984). It can also be compared to the findings of Falvo (2005) and Soulvie et al. (2012). All of them described the impacts of such kinds of stress in all facets of the whole life, including social and family relationships, economic well-being, activities of daily living, and recreational and vocational activities. Regarding emotional stress and coping strategies, the findings can be compared to those of Leske (2003). He found that most of the patients who had an accident and surgery developed grave emotional stress and coping styles within 6 to 12 months after the incidents. The stress disrupted his respondents’ capability to adapt to their family psychosocial condition. Most of them were incapable of developing encouraging relationships with their spouse and other family members. The first mother’s experience can be claimed as similar to the experiences of Leske’s respondents. This study showed that all respondents were more comfortable with the social support coping strategy. Compared with the other four mothers, the first mother seemed to cope with the self-control strategy and positive reappraisal. Within this limited initiative, the authors would argue that these findings offer important implications for practice, education, and research. Based on the findings that have been presented in the previous section, the authors suggest a number of social interventions that are believed to be useful policy implications.

Policy Implications

Integrative Social Care Initiatives

An integrated social care system is seen to be more complex because it involves the integration of formal and informal care. Overlapping of duties in both formal and informal social care systems leads to the development of an integrated social care system. An integrated social care system involves a practical partnership among formal agencies (i.e., health care agencies, public social welfare agencies, social work agencies, and social security organizations), the informal sector (i.e., voluntary organizations, charity groups, self-help groups), and the private sector (i.e., private health services). All agencies in the partnership engage in the process of delivering the services. In the local milieu, informal care is considered a complementary need to formal social care, especially after patients have been discharged from the formal social care institutions (i.e., hospital, mental institution, rehabilitation institution, prison). One important aspect that needs to be considered in the integrated system of social care is the allocation and distribution of resources. All sectors or agencies involved need to be in agreement about the ways in which physical and social resources need to be equally redistributed and utilized. In addition, social division of labor or scope of tasks and responsibilities also needs to be clearly planned so that each agency knows its function/roles.

Integration of Government Social Support Programs and Policy

An important finding of this study was that all informal caregivers involved in the study dealt with multifaceted kinds of stresses. As a result, they adopted emotional-focused coping strategies to the equilibrium in respect of their lives—physically and emotionally. Based on this important finding, the authors believe that informal caregivers need a special means of social intervention so they are found to be mostly in need of social support. Social support is the support that is provided by other people, and it arises within the context of interpersonal relationships (Hirsh, 1981, p. 151). In the local context, the Malaysian social support program for informal caregivers is categorized as home-help services, which have been implemented since 1994 under the Social Welfare Department in collaboration with the Council of Welfare Centre of Peninsular Malaysia. Their target groups are old citizens and disabled persons who live alone or with family and need support and assistance. Implementation of the program is narrow due to the shortages of volunteers. The Malaysian National Community Care Policy, which has been
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in place since the 1990s, has recognized the importance of informal care and the importance of caregivers as a source of long-term care. The policy has emphasized the importance of involving all members of the community in providing care in the community. According to the Act for Disabled People 2008, social support for informal caregivers to a disabled person is embedded in the social care services of the disabled person in care. Hence, their entitlement for services depends on the needs of the care recipient. The act also excludes people who have chronic illnesses, such as cancer and kidney disorder. Informal caregivers of those care recipients are left out of the social support services. Our view is that the coping strategies for the informal caregiving mothers’ needs should be integrated with the aforementioned national social support programs and policy. The support must be based on their needs, not on the availability of existing services and/or services embedded in the care recipients’ needs.

Instrumental Support Program for Informal Caregivers

Instrumental support is assistance provided by individuals or agencies in one’s social environment to an individual who is in need of either cash or in-kind aid (Wills, 1985). Instrumental support, either in cash or in kinds, is believed to relieve the economic burden experienced by informal caregivers. Entitled informal caregivers in advanced welfare states like Sweden, the United Kingdom, Germany, The Netherlands, and France have been supported by a series of social assistance schemes either in the form of cash or kinds since the 1990s (Da Roit & Le Bihan, 2010). In-cash social assistance is in the form of direct payments (i.e., allowances, vouchers) and indirect payments (i.e., subsidies, insurance, or tax services used), while in-kind assistance is in the form of goods or equipment required based on the immediate needs of the caregivers. The assistance can be provided by various sectors (i.e., private and nongovernmental organizations) and any other organizations at various levels of administration (i.e., central government, local authorities). Earle and Heymann (2011) and Arksey (2002), in their studies about workplace support for informal caregivers in the United States, recognized the importance of supports such as flexible working hours, paid leave for caring for ill family members or wards, and working from home, provided by employers to assist informal caregivers to be productive both at the workplace and at home. Likewise, most informal caregivers need employers to understand their problem. They need a job that is considerate of their social situation. The job needs to be flexible in terms of working hours and leave time for caregiving. A flexible employment policy for informal caregivers is to provide opportunities for them to perform their function as employees and caregivers without a conflict need to be ventured. This is because most informal caregivers are physically and mentally capable to work, and their job opportunities need to be taken into consideration seriously.

Informational Support Program for Informal Caregivers

Informational support is defined as a process in which stressed individuals will be provided with information, advice, or guidance from professional and/or semiprofessional personnel such as social workers and counselors (Malecki & Demaray, 2003; Wills, 1985). The authors would like to quote a program of informational support that is appropriate for assisting informal caregivers. The “Powerful Tools for Caregivers” (PTC) is psychoeducation and skill-generated advice or guidance provided to informal caregivers by a group of professional or semiprofessional social workers in a community-based setting. The program has been implemented by many local communities in the United States (Won, Fitts, Favaro, Olsen, & Phelan, 2008). Because informal caregivers are viewed as informed and important partners in caregiving, the objectives of PTC are to improve the care and well-being of informal caregivers. This can be achieved by providing them with knowledge and skills about emotional management, support networking, effective communication, and solving problems in a conducive manner (Savundranayagam, Montgomery, & Kosloski, 2011; Won et al., 2008). The program is a continuous process. It is presented
in six sessions, with each session held once a week for 2.5 hr in small groups. Moderators of the program include professionals such as nurses and social workers and volunteers who have been trained to work with informal caregivers. Won et al. (2008) conducted a study on the effectiveness of this program for informal caregivers. The results revealed a significant reduction in health-risk behaviors and improvement in self-care and psychological well-being after the respondents participated in PTC program.

**Appraisal Support Program for Informal Caregivers**

Social support in terms of appraisal is provided to an individual with evaluation feedback about his/her response to interventions provided (Malecki & Demaray, 2003; Wills, 1985). Other people’s assessments of informal caregivers are important to ensure effective care and to evaluate the strengths of informal caregivers. Appraisal support concentrates on individual strengths, not on the caregiver’s shortfalls (Teater, 2010). Saleebey (2009) explained that individual strengths are assessed based on the personality of the individual, his/her interpersonal relations with others, circumstances of the environment (communities and support networks) where the individual lives, culture of where the individual is a member, his/her ability, his/her level of education, and his/her employment status.

**Limitations of the Study and Directions for Future Research**

The study has a number of limitations in terms of its sampling procedure and sample selection, geographical coverage, time, and generalizability. This study included only the informal caregiving mothers whose chronically ill children were discharged from institutional services. However, the study did not cover the children at nursing homes or day-care centers. In addition, the research was done in the area of the Klang Valley in Malaysia. Perhaps because the case study focused on a single unit or a single instance, the issue of generalizability loomed larger here than with other types of qualitative research. However, much can be learned from a particular case. Readers can learn vicariously from an encounter with the case through authors’ narrative descriptions (Stake, 2005). Because the general lies in the particular, what the authors learned in a particular number of cases can be transferred to similar situations. It is the reader, not authors, who determined what could apply to his or her context (Erickson, 1986). Stake (2005, p. 455) explained how this knowledge transfer works: Case researchers “will, like others, pass along to readers some of their personal meanings of events and relationships—and fail to pass along others. They know that the reader, too, will add and subtract, invent and shape—reconstructing the knowledge in ways that leave it…more likely to be personally useful.” In addition, this study was conducted among a poor income group, whereas those who are giving care to their chronically ill children from middle- and high-income groups were not interviewed.

The special features of this case study research that provided the rationale for its selection also presented certain limitations in its usage. Although rich, thick description and analysis of a phenomenon may be desired, the authors did not have time or money to devote to such an undertaking (Stake, 2005, p. 460). The authors were the primary instrument of data collection and analysis. This has its advantages, but training in observation and interviewing, though necessary, was not readily available. The authors relied on their own instincts and abilities throughout this research effort. The authors faced what Guba and Lincoln (1981, p. 378) referred to as “unusual problems of ethics. This study selected the cases from available data that are virtually anything the authors wished could be illustrated.” The authors would agree that there might possible biases that can affect the final product. Further limitations involved the issues of reliability, validity, and generalizability. Hamel (1993, p. 23) observed that “the case study has basically been faulted for its lack of representativeness… and its lack of rigor in the collection, construction, and analysis of the empirical materials that give rise to this study. This lack of rigor is linked to the problem of bias…introduced by the subjectivity of the researcher and others involved in the case.” Furthermore, the study lacked some interrelated issues such as the factors related to mothers’ employment, noncooperation of
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the family members, and the co-occurrence and interrelatedness of mothers’ individual incapacity. The authors could not compare how these factors might affect the outcomes.

The authors mentioned that this study only included the poor income group. Further research should include mothers from the middle- and high-income groups for future research to obtain variation in the mothers’ experiences with their coping strategies. In addition, future research is suggested to involve various types of illness and a wide range of participants. The authors also propose a social mapping to facilitate the researchers in evaluating the cultural variation and community practices across different types of social classes. Future research should investigate psychosocial stresses and other associated factors in detail as the authors found that psychological stresses were higher among the mothers. More importantly, the authors suggest another investigation that could demand the suggestions of the planners, programmers, and implementation authorities toward formulating a policy in social care for the benefits of informal caregivers, patients, and families.

CONCLUSIONS

Despite a number of limitations such as a small number of sampled mothers, narrow focus, and lack of generalizability, the authors gave a snapshot of the nature of stresses involved and the coping strategies that the informal caregiving mothers followed. The study lacked focus on the factors related to their employment, non-cooperation of family members, co-occurrence and interrelatedness of mothers’ individual incapacity, and how these factors might affect the outcomes. The authors agree that a wide in-depth case study with more cases from different economical classes and geographical locations could facilitate more understanding of this particular area of study. But the strength of this study is that this finding provided some informative as well as analytical discussion in the field of informal family services for chronically ill children in Malaysia. The authors presented the social, psychological, health, and economical life burdens experienced by informal caregiving mothers. These included types and natures of stresses, depression and other serious negative health effects, as well as employment and financial insecurity.

According to the study findings, the emotional stress of caregiving is higher than other types of stresses. The study has demonstrated that caregivers have shown higher levels of depression and decreased life satisfaction over time and have demonstrated poorer physical health and health behaviors. This kind of perception may reduce the likelihood of seeking out resources and supports. Coping skills and stress management training have shown promise in improving informal caregivers’ physical and emotional health. This study showed how to enhance caregiver health, quality of life, and life satisfaction; reduce caregiver-related burden and distress; and improve access to the knowledge, resources, and tools needed to continue providing care. Comprehensible social policies that prioritize informal caregivers’ needs for social support are an influential move to improve the lives of informal caregivers. Social support programs for informal caregivers should be designed exclusively for them—not as part of social support care for other special needs such as the poor, disabled people, single mothers, and children. Based on the findings, the authors suggested a number of areas for policy implications. The authors mentioned that social care and existing governmental social support programs should be integrated and should provide more instrumental, informational, and appraisal supports to the mothers for the chronically ill and disabled children. The programs also need to be monitored in terms of their coordination with other social care agencies involved with the delivery of the services. A deeper understanding of psychosocial and stress-associated factors and the importance of community-based programs to minimize these stresses will help to develop appropriate strategies for improving care management. The study’s findings may also contribute to future research to identify and leverage coping strategies and practices that can optimize chronic illness management and social care in general.

ACKNOWLEDGMENTS

The authors would like to thank two anonymous reviewers and the journal editor for their
constructive comments. The authors also gratefully acknowledge the generosity of those mothers who participated in interviews for this study.

FUNDING

The authors acknowledge the support of the Research Unit of the University of Malaya (Special Grant for Research University [PS234/2009B]).

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