



Original Article

Coping Strategies among Family Caregivers of Patients with Chronic Illness: A Qualitative Grounded Theory Study

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ABSTRACT

Objectives: This study aimed to explore the coping strategies of family caregivers with chronic illness patients in Malaysia.

Materials and Methods: The current study employed an inductive approach, specifically the grounded theory method. A total of 33 respondents were involved in this study, consisting of 24 family caregivers and nine professional helpers from diverse backgrounds. All respondents were recruited through purposive and theoretical sampling based on specified criteria. Data collection and analyses were carried out using semi-structured interviews and memos. Data analyses were assisted by NVivo 12 software. Several measures were undertaken to ensure the credibility and trustworthiness of the data.

Results: Findings revealed four main coping strategies employed by family caregivers. It includes (1) support systems, (2) positive behaviour, (3) spiritual and (4) self-adjustment. Support systems comprise family, friends, employer and community. Positive behaviours include self-care practices, including seeking help from professional helpers, managing personal stress, emotional expressions and engaging in journal writing. Spirituality involves faith in God and religious practices, while self-adjustment consists of emotional and cognitive adjustment.

Conclusion: This study contributes to the literature by providing new insights into the coping strategies used by family caregivers in the Malaysian context. The findings suggest that coping strategies should be individually investigated and adapted based on personal preferences and context. It offers valuable implications for nursing practices, particularly in providing a basic guideline for them to work with patient caregivers.

Keywords: Chronic illness, Coping skills, Family caregiver, Grounded theory, Qualitative research

INTRODUCTION

The global burden of chronic illnesses such as cardiovascular diseases, cancer, diabetes and chronic respiratory diseases has escalated which then positioning them as the foremost cause of death globally.^[1] The prevalence of chronic illnesses continues to increase each year, exerting a significant impact on the range of sectors, including the economy in many countries.^[2] This rising load has led to an increased patients' reliance on their caregivers. Caregivers play an important role in supporting patients' daily functioning by offering a range of assistance, including emotional, physical and social support.^[3] Nonetheless, the caregiving role is often associated with considerable burdens, such as financial issues,^[4] emotional and psychological strain,^[5] health issues,^[6] and social isolation. Lack of emotional and social support received by caregivers intensifies the burden that

they carry. All the challenges encountered by caregivers are closely linked to their overall quality of life.^[7] In the absence of appropriate coping strategies, caregivers are likely to experience significant mental health challenges. Therefore, it is essential to determine effective coping strategies for caregivers. However, it should be acknowledged that the coping strategies are not one size that fits all; they must be adapted to suit individuals' varying life situations and personal strengths.

Caregivers often face considerable emotional demands; hence, coping strategies play an important role in buffering caregivers from psychological stress and emotional burden. Studies have consistently found that the use of adaptive coping mechanisms such as positive reframing and acceptance is effective in reducing stress. Conversely, maladaptive coping responses such as substance abuse and self-distraction tend

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to exacerbate stress and burnout.^[8] While caregivers adopted effective coping practices, their mental stability and well-being improved, enabling them to provide effective care to the patient. Over time, coping skills serve as an important preventative measure against mental health issues among caregivers. Understanding the coping strategies adopted by caregivers is therefore essential, as it has a positive impact on both the caregiver and the care recipient. However, while caregiving is a common experience, there remains a limited understanding of how Malaysian caregivers manage the persistent stress associated with chronic illness caregiving. Research in coping strategies among Malaysian caregivers remains sparse and insufficiently grounded in the local cultural and healthcare context. Caregivers in Malaysia may utilise a range of coping strategies that are deeply shaped by cultural and religious norms. However, the persistent burden and mental health challenges among caregivers point to the urgent need for more targeted research to inform culturally relevant and effective support systems. Therefore, this study sought to investigate the coping strategies used by family caregivers of chronic illness patients through an inductive lens, by employing a grounded theory approach. Consistent with grounded theory principles, the initial review of literature and theoretical frameworks was deliberately limited, focusing solely on general aspects of chronic illness and the methodological foundations of grounded theory. This approach was adopted to minimise the potential influence of pre-existing theories or findings on the researcher's analytical perspective.^[9]

MATERIALS AND METHODS

This study received ethical approval from the University Research Ethics Unit (UM.TNC2/UMREC-996). Caregivers were informed about the study's objectives, procedures, ethical considerations and other important aspects, and all of them signed the informed consent. We employed the classic grounded theory (Glasserian) method to develop a framework that elucidates the coping strategies of family caregivers. This approach was chosen due to its ability to generate a framework directly from data, which is particularly useful to investigate less-studied experiences such as caregiving. It allows researchers to develop new and original insights based on participants' lived experiences, without relying on pre-existing models.

Informants

We employed purposive sampling for initial participants and theoretical sampling for subsequent recruitment. Five criteria were specified to choose initial participants: (1) the patient had a chronic illness, particularly a progressive illness; (2) the patient required daily support; (3) the caregiver was a family member; (4) home-based caregiving; and (5) at least 6 months of caregiving experience. We used theoretical sampling to guide the data collection process,^[9] which

helps researchers decide what data to gather next. As data collection progressed, the professional helpers were included due to their direct involvement with caregivers. In total, 33 participants took part in the study, consisting of 24 caregivers and nine professional helpers.

Data collection and analysis

Semi-structured interviews and memos were the main data collection methods. Interviews allowed for deep insights into caregiving experiences, while memos captured researchers' reflections during the data analysis process, particularly in tracking emerging codes, concepts, categories, similarities and differences.^[9] The data analysis process started immediately after the first interview was completed. NVivo 12 software facilitated the organisation and analysis of the data. Researchers independently familiarised the raw data to gain an understanding. We started the first step in data analysis with open coding by examining the transcripts line-by-line to identify the important key. After open coding, researchers collaboratively discussed and refined the codes. Thus, the axial coding was conducted to identify categories and themes derived from the previous phase, wherein categories represent significant data patterns. Relevant codes were categorised into one core category, followed by selective coding, where categories were linked into a main category. Three experts in family therapy and qualitative perspectives contributed to the analysis, ensuring the study's credibility. Continuous comparisons of codes, concepts and categories were made across transcripts based on the Constant Comparison Method.^[10,11] Data collection continued until data saturation was confirmed through the redundancy in the findings, with no new themes or concepts emerging from the interviews. In this study, saturation was reached after 33 interviews. Interviews 1 through 4 identified support systems and positive behaviour themes, with new themes emerging regularly as participants navigated their caregiving journey, while interviews 5 through 9 showed the emergence of the spiritual theme. As data collection resumed, participants' reflection deepened and support systems, positive behaviour and spiritual themes were strongly manifested by interviews 15 through 19, indicating partial saturation. By interviews 20 through 24, the theme of self-adjustment was evident, and no new themes appeared. Saturation was further confirmed by interviews 30 through 33, where patterns remained consistent, and no additional concepts emerged.

Trustworthiness

The study's transferability and credibility were enhanced by the use of theoretical sampling, data collection methods and rigorous analysis processes. Peer review and expert discussions ensured methodological consistency and minimised bias. Peer debriefing further reduced subjectivity, while triangulation across multiple sources, methodologies and analyses enhanced the credibility of the findings.

RESULTS

Participants' background

The sample comprised 24 caregivers, most of whom were female ($n = 19$, 79.2%) and Malay ($n = 20$, 83.3%). The remaining participants were Indian ($n = 3$, 12.5%), followed by Chinese ($n = 1$, 4.2%). Ages ranged from 19 to 65 years ($M = 38.5$). The majority were married ($n = 17$, 70.8%), with the rest being single ($n = 4$, 16.7%) or single mothers ($n = 1$, 4.2%). Participants' occupations varied, and caregiver-patient relationships were predominantly parent-child ($n = 20$, 83.3%), with others including grandchild ($n = 3$, 12.5%), spouse ($n = 1$, 4.2%) and daughter-in-law ($n = 1$, 4.2%). Table 1 summarizes the key characteristics of caregivers' background.

The professional helper sample comprised nine participants, most of whom were female ($n = 7$, 77.8%) and Malay ($n = 9$, 100%). Their professional backgrounds included psychology officers ($n = 5$, 55.6%), nurses ($n = 3$, 33.3%) and medical social worker officers ($n = 2$, 22.2%). Years of experience ranged from 2 to 16 years ($M = 8.2$ years), with work settings spanning health clinics, psychiatric wards, rehabilitation clinics, geriatric wards, paediatric wards and patient care centres. Table 2 provides an overview of professional helpers' background.

Key themes

Four main categories of coping skills emerged from the analysis, namely (1) support systems, (2) positive behaviour, (3) spiritual and (4) self-adjustment.

i) Support systems

Four sub-categories have emerged under the support systems, which are emphasised in the sources of support systems. Sources of support systems include of caregiver's family, friends, employer and the caregiver's community. Most caregivers said that the continuous support that they received from those parties played a crucial role in their caregiving lives. Some of the participants said:

"We need to have emotional support from our significant people, our backbone. Our family, right? Especially our partner." -CG05

"So I think what I need to find is a support system, which is my friends".- CG16.

"However, thank God my employer is understanding. If I can't go to the office, I can still work from home."-CG13.

"I joined a group that was established in the US, so there was a dementia caregiver support group, so I could express my feelings there." -CG03.

ii) Positive behaviour

Caregivers practised positive behaviours to maintain their well-being. Such behaviours serve as a source of motivation, fostering greater resilience in their caregiving roles. In this study, positive behaviour encompassed various self-care practices, including seeking help from professional helpers, managing

personal stress, emotional expressions and engaging in journal writing. A few participants shared:

"... if possible, immediately find. you can get counselling services if needed.get counselling services." - CG22.

"...if I categorise emotional support, we can have individual counselling sessions to support our emotions." - PH03.

"I have a very close volunteer friend, and I will contact him and share everything that happened. And he has lent his ear to listen to my sharing." - CG22.

"Then I found that writing is one of the healing methods for me." - CG22.

iii) Spirituality

Faith in God and religious practices were important coping strategies for many caregivers. Although caregivers faced many challenging situations in caregiving life, spirituality guides them to be patient and accepting of qada' and qadr that were destined for them. When in a difficult situation, they return to God and pray, which allows them to gain inner strength. Several participants noted that:

"I always think that God gave me this test, maybe to bring me closer to Him, to be more responsible in taking care of a special child, because before, I was just having fun and not thinking about commitment" - CG13

"Be patient and strong because we must think that this is a trial for us, not the parents. God chose us because there is a reward for it" - CG15

"Send lots of salawat and dhikr." - CG12

Caregivers engaged in practices such as redha (acceptance) and tawakkul (trust in God, reliance on God), doa (prayer), salawat (sending blessings upon the Prophet) and dhikr (remembrance of God).

iv) Self-adjustment

In the caregiving process, caregivers gradually develop self-adaptive skills that help them better endure and respond to the demands of caregiving. This adaptation encompasses both emotional and cognitive components. A few participants remarked that:

"... the process was very fast, so I'm constantly making adjustments, not only to my life routine, but also TO my emotions." - CG22

"So when this thing happened in my life, at first I thought, oh God, why are You testing me? But later I realised if He hadn't given me this test, I don't know what I would be right now. So, I now see what happened in my life from a positive side." - CG16.

DISCUSSION

Support systems play a vital role in promoting the well-being and emotional resilience of caregivers, particularly those

Table 1: Caregivers' profile.

ID	Gender	Ethnicity	Occupation	Relationship status	Relationship to patient
CG01	Female	Malay	Part-time teacher	Married	Child
CG02	Female	Malay	Lecturer	Married	Child
CG03	Female	Malay	Student	Married	Child
CG04	Female	Malay	Not working	Single	Child
CG05	Female	Malay	Part-time salesman	Married	Child
CG06	Male	Malay	Retired	Married	Husband
CG07	Male	Malay	Teacher	Married	Child
CG08	Female	Malay	Housewife	Married	Child
CG09	Male	Malay	Student	Single	Child
CG10	Female	Malay	Teacher	Married	Adopted Child
CG11	Male	Malay	Technician	Married	Child
CG12	Female	Malay	Not working	Single mother	Child
CG13	Female	Malay	Engineer	Married	Child
CG14	Female	Malay	Housewife	Married	Child
CG15	Female	Malay	Student	Married	Grandchild
CG16	Female	Malay	Student	Single	Child
CG17	Male	Malay	Self-employed	Married	Child
CG18	Male	Malay	Sales Executive	Married	Child
CG19	Female	Malay	Sales Executive	Married	Child
CG20	Female	Malay	Insurance consultant	Married	Child
CG21	Female	Indian	Student	Single	Grandchild
CG22	Female	Chinese	Self-employed	Married	Child
CG23	Female	Indian	Student	Single	Grandchild
CG24	Female	Indian	Factory worker	Married	Daughter-in-law

Table 2: Professional helper profile.

ID	Gender	Ethnicity	Occupation	Years of experience	Job setting
PH 01	Female	Malay	Psychology officer	3 years	Health clinic
PH 02	Male	Malay	Psychology officer	8 years	Psychiatry ward and clinic
PH 03	Female	Malay	Nurse	2 years	Patient care centre
PH 04	Female	Malay	Psychology officer	13 years	Psychiatry ward and outpatient
PH 05	Male	Malay	Medical social worker officer	12 years	Renal and Geriatric ward
PH 06	Female	Malay	Psychology officer	10 years	Rehabilitation Clinic
PH 07	Female	Malay	Nurse	7 years	Paediatric ward
PH 08	Female	Malay	Nurse	3 years	Patient care centre
PH 09	Female	Malay	Medical social worker officer	16 years	Geriatric ward

caring for chronically ill patients. Support systems consist of family members, friends, employers and a caregiver support group. Family members fulfil both emotional and physical needs, thereby helping to alleviate caregiver stress. Friends often serve as informal sources of support, providing a platform for social interaction. In addition, employers are essential to provide various forms of job benefits such as unrecorded leave, flexible working arrangements and

other workplace benefits. Support groups made up of fellow caregivers offer a valuable coping strategy, allowing caregivers to exchange experiences and thoughts, gain insights and acquire new knowledge among those who face similar challenges.^[12] On the other hand, practising positive behavioural strategies such as self-care is important. The practice of self-care, such as seeking professional help from counsellors or therapists who can offer psychological

support, is one of the strategies that can help caregivers in maintaining their well-being. In addition, caregivers reported that they engaged in stress management techniques in difficult situations. Caregivers also allowed themselves to acknowledge and express their feelings through various platforms, such as journal writing. Undeniably, practising self-care behaviours has been linked to improved caregiver well-being, greater preparedness and enhanced decision-making.^[13,14] These strategies not only benefit the caregivers themselves but also indirectly enhance the quality of care provided to patients.

Our findings also highlighted that religious coping strategies are among the most common strategies practised by caregivers. Some caregivers who have good trust in God believe that God knows what is best for them, even in a hard time. They learnt to accept what God has determined for them. In difficult times, caregivers often return to God by practising religious acts such as prayer and dhikr. By doing that, they get a sense of peacefulness that they did not get through other means. The inner peacefulness helped them in finding meaning in the purpose of the caregiving role, thereby fostering the inner strength in facing caregiving challenges.^[15,16] Meanwhile, the ability of caregivers to adjust themselves in difficult situations is crucial. Self-adjustment can be defined as an individual's ability to regulate emotions, thoughts and behaviours to respond more effectively to caregiving demands. This ability includes the ability to manage own emotions, such as sadness, anger, frustration and guilt. All of these emotions, if left untreated, can be a risk factor for mental issues, thereby affecting the quality of care provided. In addition, cognitive coping strategies such as accepting reality and finding meaning in the caregiving journey may substantially contribute to stabilising emotion and well-being.^[17]

The current findings offer several theoretical implications. Notably, there is a meaningful connection with Pearlin's Stress Process Model for Caregivers.^[18] This model identifies multiple sources of caregivers' stress, including contextual factors, and both primary and secondary stressors, which are reflected in the emerging themes in our analysis. However, these sources do not necessarily lead to significant stress if caregivers possess effective coping skills. In the present study, we illustrated how coping strategies were applied in the lived experiences of caregivers, which could potentially mitigate the impact of stressors. This also indicates Pearlin's premise that coping strategies as mediators between stress and caregiver outcome, which can enhance resilience. Second, the support systems as a coping strategy by caregivers can be reflected with structural family therapy (SFT).^[19] Family dynamics are integral to the caregiving context. Each family subsystem, such as the marital, parental and sibling subsystems, plays its role in the family. Well-functioning family systems may serve as vital support sources and become a powerful coping

strategy for caregivers. This supports the SFT proposition that the functionality of family subsystems is not only a structural element within the family but also a determining factor in a caregiver's coping.

An in-depth understanding of the coping strategies of family caregivers is crucial. The insights of lived experiences of family caregivers and their coping strategies may help counsellors in their counselling process, as they provide a basic guideline for counsellors and other caregivers in understanding the caregivers' struggles. Furthermore, other caregivers may consider adopting or adapting these coping strategies to manage their caregiving responsibilities more effectively. The findings also contribute meaningfully to the enhancement of nursing practices in the management of chronic illness. The coping strategies identified through this study may inform nursing professionals of approaches that can be integrated into their practice when dealing with patients and supporting caregivers. This information can also be communicated to patients and their families as part of the preparation and support provided for caregiving tasks, ultimately promoting better caregiver well-being and patient care outcomes.

In this study, we identified a few limitations that need consideration for future researchers interested in conducting a similar study. This study is conducted within Malaysia's sociocultural context, which is characterised by collectivist norms and strong religious beliefs. These norms and values shaped the caregiving roles and coping strategies of caregivers. However, the predominance of Malay and Islamic participants impedes the breadth and representativeness of the findings. In light of these limitations, future research should therefore consider undertaking comparative studies involving caregivers from different cultural backgrounds. Such comparisons could yield more comprehensive and culturally grounded insights into caregiving practices. Inclusion of the voices of care recipients would allow for data triangulation and enrich the understanding of the caregiver-patient dynamic and the extended care network. Targeted recruitment in multi-ethnic and religious groups can ensure the inclusion of a broader study population.

CONCLUSION

This study offers detailed insight into the coping strategies used by family caregivers in managing the care of patients with chronic illnesses in Malaysia. The grounded theory method was used to document their lived experiences, which are influenced by multiple circumstances. The findings suggest that there is no single, universally effective coping strategy that is equally successful for all caregivers. Instead, these strategies should be tailored to individual preferences and context. Therefore, it is important to begin with the dissemination of relevant knowledge, sharing caring experiences and providing accessible psychoeducation to

empower and support caregivers in their roles. Integrating culturally sensitive coping strategies into nursing practice and community-based services could strengthen caregiver resilience, thereby contributing to improved patient care quality in Malaysia.

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