

Navigating The Journey: Exploring The Personal Experiences and Psychological Needs of Informal Caregivers

Nur Syafiqa Hazira Yusri, Rozainee Khairudin

Centre for Research in Psychology and Human Well-being, Faculty of Social Science and Humanities, Universiti Kebangsaan Malaysia

Corresponding Author Email: nursyafiqahazira@gmail.com

To Link this Article: <http://dx.doi.org/10.6007/IJARBSS/v14-i5/21605>

DOI:10.6007/IJARBSS/v14-i5/21605

Published Date: 25 May 2024

Abstract

This research was carried out to explore the personal experiences and psychological needs of informal caregivers of individuals with depression. As fulfilling as providing good care for the loved one, caring for a person with depression can be demanding and stressful. Caregivers may experience a range of physical, emotional, and social challenges due to their caregiving responsibilities. Therefore, this research aims to understand and explore their personal experiences and psychological needs to effectively support informal caregivers of individuals with depression who are at risk of burnout. This study involved eight participants who engaged in in-depth interviews, analysed using thematic analysis via online meetings. The personal experiences and psychological needs of informal caregivers of individuals with depression can be summarized into five themes: (1) awareness and knowledge of the changes in behaviour and personality of family members with depression, (2) emotional difficulties, (3) communication skills, (4) balancing personal needs and the needs of family members with depression, and (5) stigma and social support. In conclusion, the research highlights the need for tailored coping strategies and support mechanisms for informal caregivers.

Keywords: Personal Experiences, Psychological Needs, Informal Caregivers, Depression

Introduction

The COVID-19 pandemic has substantially impacted global mental health, resulting in a notable increase in anxiety and depressive disorders, with a reported 28% rise in major depressive disorders within a year, according to the World Health Organization. The pandemic-induced uncertainty, fear, physical isolation, and social distancing measures have contributed to feelings of loneliness and depression. Consequently, there is a growing demand for informal caregivers—typically friends or family members—who play a crucial role in supporting individuals with depression. These caregivers, often referred to as the "invisible healthcare system," Arno et al (1999) provide unpaid assistance, including help with daily

activities and emotional support. Despite their significant contributions, informal caregivers often go unnoticed and unrecognized by the formal healthcare system.

The data from the National Health and Morbidity Survey (NHMS) 2019, interestingly note that 5.7% of the adult population in Malaysia were informal caregivers. Informal caregivers play a critical role in supporting individuals with health or social care needs, and the demands of caregiving can have significant impacts on their physical and mental health. As fulfilling as providing good care for the loved one, caring for a person with depression can be demanding and stressful, and caregivers may experience a range of physical, emotional, and social challenges as a result of their caregiving responsibilities. These challenges can include increased risk for depression and anxiety, social isolation, financial strain, and reduced quality of life (Balkaran et al., 2021). It is important to recognize the significant contributions of informal caregivers and to provide them with adequate support and resources to help them manage their caregiving responsibilities and maintain their well-being. Informal caregivers of individuals with depression often face a range of stressors, including providing care for a loved one who may be experiencing severe symptoms, managing their own emotional reactions to the care recipient's depression, and dealing with the stigma and lack of understanding associated with mental illness. These stressors can contribute to feelings of exhaustion, frustration, and helplessness (Martínez et al., 2020). Research has shown that burnout among informal caregivers of individuals with depression is associated with a range of negative outcomes Kindt et al (2015), including increased risk of depression and anxiety, decreased quality of life, and decreased ability to provide effective care. Additionally, burnout can lead to feelings of guilt Misiolek-Marín et al (2020), which can further exacerbate caregiver stress and contribute to a sense of isolation. In conclusion, burnout is a common experience among informal caregivers of individuals with depression, and it can have negative impacts on the caregiver's mental and physical health Bauer & Sousa-Poza (2015), as well as their ability to provide effective care.

To effectively support informal caregivers of individuals with depression, it is crucial to understand and explore their specific needs and challenges. The caregiving journey can be emotionally and psychologically demanding Faronbi et al (2019), as caregivers provide care and support to their loved ones who are experiencing depression. These caregivers often witness the emotional struggles and challenges faced by the care recipients, which can be distressing and draining for them. The constant emotional entanglement with the care recipient's well-being can significantly impact the informal caregivers' mental health and overall quality of life. Caregivers may experience increased risk for depression and anxiety, social isolation, financial strain, and reduced quality of life (Balkaran et al., 2021). They may feel overwhelmed by the responsibilities and challenges they face while trying to support and assist their loved ones in coping with depression. Moreover, the cyclical and ongoing nature of caregiving for individuals with depression means that caregivers may not have regular breaks or opportunities to recharge, leading to increased burnout risk. Therefore, the current research focuses on the objective of exploring the personal experiences and psychological needs of informal caregivers who are at risk of burnout.

Research Method

Design and sample

The study involved in-depth interviews of a total of 8 informal caregivers, who were individually interviewed. The selection of participants followed a purposive sampling approach, aiming to include individuals with relevant experiences and insights related to

caregiving for individuals with depression. The participants were screened for eligibility before being invited to participate in the qualitative method. The inclusive criteria were:

1. Age eligibility required individuals to be 18 years or older.
2. Residing in Klang Valley.
3. Willingness to communicate and cooperate was an important characteristic.
4. Providing care to the patient for a minimum of three months was a requirement.
5. Direct responsibility for the patient's care was essential.
6. Consent to participate in the study was necessary.

The sample size depended on the saturation of the data. According to Fugard and Potts (2015), it was recommended to conduct interviews with a group of 6 to 10 participants for smaller projects. This qualitative research involved a total of 8 participants to achieve the research objective.

Potential Ethical Concerns

Maintaining confidentiality in online interviews was crucial due to the risk of unauthorized access. To address this concern, researchers emphasized the use of secure platforms, private settings, and strict measures to protect participants' personal information. This included secure storage, restricted access, and coding or anonymizing data during analysis. The study also highlighted a commitment to participant privacy by prohibiting information sharing with third parties and securely disposing of all collected data at the study's conclusion.

Analysis

The researchers personally transcribe the recorded interview videos verbatim using Google Docs. The researchers carefully listen to the video recordings multiple times to ensure accuracy and become familiar with the data. The transcribed data will then be imported into NVivo 12, a qualitative data analysis (QDA) software, which will assist in organizing and analysing the data. The process begins with open coding, where the transcripts are examined line by line and participants' exact phrases are used as initial codes. Codes that share similarities will be grouped under the same themes, while those that do not match will be assigned to new themes. These themes will be further analysed to determine if they fit into broader categories. Throughout the analysis, the data will be continuously revisited and reviewed to ensure a refined and credible qualitative analysis, adhering to the principles of credible in qualitative research.

Findings

A total of 8 informal caregivers engaged with in depth interviews. The respondent's background was tabulated in Table 1 to help the reader visualize the relationship between the respondents and their family members who are depressed. Meanwhile, Table 2 aids in the graphical representation of the surfaced themes and subthemes derived from the study.

Based on the verbatim using Thematic Analysis related to Personal Experiences and Psychological Needs among respondents, found that respondents experienced the struggle of navigating (1) the changes in behaviour and personality of family members with depression, (2) emotional difficulties, (3) lack of communication skills, (4) balancing personal needs versus family member with depression and (5) stigma and social support.

Table 1

Background of the respondents

Respondents	Background
P01	Younger sister to a depressed brother. Her brother has been depressed for over 3 years.
P02	Mother to a depressed daughter. Her daughter has been depressed for over 5 years.
P03	Younger sister to a depressed brother. Her brother has been depressed for over 3 years.
P04	Younger sister to a depressed older sister. Her sister has been depressed for over 2 years.
P05	Brother of a depressed older sister. His sister has been depressed for over 6 years.
P06	Older sister to a depressed brother. Her brother has been depressed for over 3 years.
P07	Daughter of a depressed mother. Her mother has been depressed for over a year.
P08	Mother to a depressed daughter. Her daughter has been depressed for over 4 years.

1. Awareness & Knowledge of the Changes in Behaviour and Personality of Family Members with Depression

The research reveals that Informal Caregivers of Individuals with Depression demonstrate a notable deficit in awareness and understanding of depression's signs and symptoms, particularly those contributing to observable behavioural changes. This deficiency is attributed to multiple factors, encompassing a limited comprehension of mental health nuances, societal stigmatization of mental illnesses, and a paucity of exposure to pertinent information about depression and its manifestations. Despite Informal Caregivers acknowledging alterations in the behaviour and demeanour of individuals with depression, a recurrent failure to attribute these changes to the condition itself is observed. Participant P02's testimonial underscores the challenges encountered in comprehending the depressive state, as articulated through a linguistic struggle to describe the foundational factors precipitating her daughter's behavioural shifts. P02 consistently describe her experiential challenge in fathoming the complexity of her daughter's behaviour consequent to depression, employing linguistic formulations such as "I didn't understand" and "it was difficult."

"In terms of behaviour, she has indeed changed. It's like she's sick. She likes to sit alone, be by herself. There's less interaction and conversation even with family members. At first, I didn't understand. So, it was really difficult. This was something new. So, there were a lot of things I didn't understand. I wasn't able to understand what she was going through. And at the beginning, my relationship with her was really bad. It's like I really don't know her behaviour, is it a hormone issue, is it just a normal teenage problem, or is it really a mental health issue. At the beginning, I didn't understand either. So, it was really difficult."

Moreover, participant P06 provided insights into her experiences regarding her younger brother's depression, highlighting a significant change in her family member with depression, who was initially lively and cheerful but became withdrawn and less talkative. The family noticed this shift as the individual isolated himself in his room and exhibited a different demeanour. Despite reassurances that he was okay, the family recognized that their loved one was not his usual self. Emergence data as below

“He was very active. He was like the clown of the family, you know, always cheerful and lively. But after that, he started distancing himself. Even when I come home from work, I rarely see him. He's not around, not in the common areas, not in the living room, not in the kitchen, just in his room. When we spend time together, he becomes more quiet and less talkative. So, when any family member asks if he's okay or not, he says he's okay, but he's not the same person he used to be. It's like we all feel the impact of his change.”

2. Emotional difficulties

The interviews conducted to all of the participants clearly indicate that Informal caregivers of individuals with depression often face various emotion-related challenges. These difficulties can arise due to the demanding nature of caregiving responsibilities, the complex and unpredictable nature of depression, and the emotional toll of witnessing a loved one's struggle. Informal caregivers of individuals with depression often face heightened emotional stress, experiencing a range of challenging emotions such as sadness, helplessness, and frustration. The responsibilities of providing care and supporting their loved ones through depressive episodes can become overwhelming, adding to their emotional burden. Moreover, Informal caregivers may encounter difficulties in comprehending and interpreting the emotions expressed by the individual with depression, further contributing to their emotional challenges. The participant P06 provided insights into how another person's emotions affected both themselves and their household. She expressed a genuine desire to offer assistance while also recognizing the emotional burden it placed on her. Additionally, P06 described experiencing mixed feelings of discomfort and concern in response to the individual's emotional outbursts

“He also affects our emotions. Because we know he's in pain, and we don't want to see him sad. So it feels a bit suffocating in that house. But at the same time, you want to help him, but we also feel the pain because sometimes, he cries in his room. And my room is just next to his. So when he cries or screams, it makes me uncomfortable. So sometimes, when I try to check on him, he acts normal again, so when I ask him to talk about it, he doesn't want to. I felt a bit disturbed sometimes a bit uncomfortable.”

Informal caregivers of individuals with depression often face heightened emotional stress, experiencing a range of challenging emotions such as sadness, helplessness, and frustration. The responsibilities of providing care and supporting their loved ones through depressive episodes can become overwhelming, adding to their emotional burden. Moreover, Informal caregivers may encounter difficulties in comprehending and interpreting the emotions expressed by the individual with depression, further contributing to their emotional

challenges. Participant P08 expressed her struggle in comprehending her daughter's emotions, stating,

"I find it challenging to understand her mood. It's hard to understand someone's mood like this."

Communication skills

Communication plays a crucial role in building understanding, trust, and support within relationships, especially when dealing with mental health challenges. It helps to understand and validate the loved ones and the Informal Caregivers own emotions, offer empathetic support, and provide an environment where open discussions about mental health can take place. The interviews revealed a consistent pattern where individuals with depression often encounter difficulties in expressing their feelings and thoughts due to the nature of their condition. This may manifest as withdrawal, difficulty articulating emotions, or struggling to communicate their needs effectively. For Informal Caregivers with poor communication skills, these barriers can make it even more challenging to navigate conversations and establish a meaningful connection with their loved ones who are experiencing depression. During the interview with P04, she opened up about the shared struggle among the siblings and parents when faced with the daunting task of approaching their loved one who was dealing with depression. The Informal Caregivers found themselves in a challenging situation, uncertain about what to say or how to initiate meaningful conversations. This lack of communication skills created a barrier, leaving them feeling unsure and searching for effective ways to support their loved one:

"Siblings don't know what to do. Mom and Dad also don't know what to do, and we also don't know what to do. None of us know what to say."

Similarly, in P03's experience as an Informal Caregiver, she recounts her experience of communicating with her depressed loved one where she describes that experience,

"Even if we talked to him, he would act foolishly. Or he would just remain silent. There was no two-way communication, no solution."

4. Balancing Personal Needs and the Needs of Family Members with Depression

Informal caregivers often struggle with the challenge of balancing their personal needs with the needs of their family members who are experiencing depression. Being a caregiver requires dedicating significant time, energy, and resources to provide support and care to their loved ones. However, this can lead to neglecting their own well-being and personal needs. The demands of caregiving can be overwhelming, both emotionally and physically. Informal caregivers may find themselves constantly prioritizing the needs of their family members with depression, leaving little time and energy for self-care and attending to their own personal needs. This can result in increased stress, burnout, and a decline in their quality of life. Participant P05, being the only son in his household, indirectly revealed the burden of conforming to traditional gender expectations, specifically the notion of "being a man" within the family. This internalized pressure may lead to feelings of guilt or selfishness when he considers his own needs, as he prioritizes the well-being of his family members above his own.

Consequently, this pattern can contribute to neglecting his own self-care and sacrificing his personal well-being, further exacerbating the challenges he encounters:

“Even though I'm supposed to go to the clinic, I didn't go until now. Even when I was supposed to have a checkup, I didn't go until now. I didn't have time. Ever since the start, there's been a lot of things happening. My sister has her own problem and she didn't take it well. I also have my problem and if I also didn't take it well, then there's nobody going to be well.”

Participant P07 provided valuable insights into the conflict that arises when trying to balance personal needs with the needs of a family member with depression. She highlighted the challenge she faced as a daughter in expressing any discomfort or displeasure regarding the behaviour or actions of her elderly mother. This limitation made it difficult for P07 to address her own needs and advocate for the well-being of her depressed mother.

“My mother, she's the type when she's depressed, she would stay up all night. I would sleep on the same bed as her. So, when she stayed up, sometimes she would wake me up, and she would complain, saying that she's in pain, that she's not feeling well. I am like she's my mother, I have to be patient, but there are certain moments where I just stay silent. Because I am tired, I came back from work and everything.”

5. Stigma and Social Support

Informal caregivers of individuals with depression often experience a decline in overall well-being due to stigma and lack of social support. Stigma surrounding mental health creates shame and hinders informal caregivers from seeking help or discussing their role. This isolation contributes to increased risk of burnout. Moreover, limited social support deprives informal caregivers of resources and understanding, leaving them overwhelmed and unsupported. The combination of stigma and lack of social support intensifies the negative impact on caregivers' well-being. The participant P01 expressed another challenge she faced in communicating with their depressed loved one, which was the lack of acceptance from their family. In the early stages, even the P01's parents struggled to understand what depression disorder truly entailed. While P01's parents had some knowledge about it, they were reluctant to acknowledge that their son had been diagnosed with such conditions. This lack of acceptance from the family added an additional layer of difficulty in openly discussing and addressing the mental health issues their loved one was facing:

“Another thing is the acceptance of my extended family. Because at the initial stage, even my parents didn't understand what depression disorder is. They didn't comprehend it. They knew about it, but they didn't want to admit that their son was diagnosed with those conditions.”

The participant P08 believes that there is still a lot of work to be done to reduce stigma and discrimination against individuals with mental health issues and to increase the availability of social support.

“There is no support. Ideally, there should be support, but it's not happening. So, I feel that we still have a long way to go. This mental health issue is actually very serious, but we still have a very long way to go.”

Table 2
Themes and subthemes

Themes	Subthemes
1. The changes in behaviour and personality of family members with depression	1.1 Struggle to comprehend the behavioural changes 1.2 Impact on family dynamic 1.3 Recognition of Changes versus Understanding Depression
2. Emotional difficulties	2.1 Struggle to comprehend the depressive mood 2.2 Impact on informal caregivers’ emotional well-being 2.3 Balancing the urge to help with emotional strain
3. Lack of communication skills	3.1 Challenges in Initiating Meaningful Conversations 3.2 Communication Barriers Faced by Individuals with Depression 3.3 Impact of Poor Communication Skills on Supportive Relationships
4. Balancing personal needs versus family members with depression and	4.1 Gendered Expectations and Self-Sacrifice 4.2 Cultural Norms and Limited Expression of Discomfort 4.3 Overwhelming Demands of Caregiving

5. Stigma and social support

5.1 Family Acceptance and Stigma

5.2 Perceived Lack of Social Support

5.3 Stigma's Impact on Help-Seeking Behaviour

Discussion

The study explored the personal experiences and psychological needs of Informal Caregivers of Individuals with Depression using Thematic Analysis of the verbatim data pertaining to participants' personal experiences and psychological needs, the researchers identified several common challenges. These challenges encompassed navigating the (1) Awareness & Knowledge of the Changes in Behaviour and Personality of Family Members with Depression, (2) Emotional Difficulties, (3) Communication skills, (4) Balancing Personal Needs and the Needs of Family Members with Depression, and (5) Stigma and Social Support.

The findings indicate that Informal Caregivers of Individuals with Depression have limited awareness and knowledge regarding the signs and symptoms of depression. Informal Caregivers may observe behavioural changes like withdrawal, irritability, or loss of interest, but they may lack a comprehensive understanding of the underlying psychological factors associated with depression. The lack of awareness and knowledge of informal caregivers regarding the signs and symptoms of depression can be attributed to various factors, one of which is the influence of traditional beliefs and cultural norms (Bracke, Delaruelle & Verhaeghe, 2019). In a study by Konerding et al (2018), the way caregivers perceive the normality or abnormality of the tasks they perform in a sociocultural context and the sacrifices they make due to caregiving can also influence their evaluation of the situation. In many cultures, including some Asian cultures, mental health disorders are often stigmatized and attributed to supernatural or moral causes, such as bad karma or divine punishment (Lehtonen, 2022). These beliefs create a perception that individuals with mental health issues are morally flawed or deserving of their condition. As a result, informal caregivers may internalize these cultural beliefs and view their loved ones' mental health struggles through a moral or spiritual lens rather than recognizing them as symptoms of a medical condition. Consequently, Informal caregivers may hesitate to seek help or openly discuss their family member's mental health concerns due to the fear of being judged, ostracized, or viewed as morally deficient. This cultural stigma further perpetuates the lack of awareness and knowledge surrounding depression among informal caregivers. To mitigate the risks associated with the traditional beliefs and cultural norms, it is crucial for informal caregivers to receive education and training on depression, including its symptoms and available treatment options. By promoting access to evidence-based information, the module can contribute to better-informed decision-making, improved caregiving practices, and ultimately, enhanced outcomes for individuals experiencing depression and their caregivers. Supported by Zhou et al (2021) findings that family caregivers who possessed enhanced caregiving knowledge and skills tended to adopt positive coping mechanisms, leading to better mental well-being.

Witnessing a loved one's struggle with depression can be emotionally challenging for caregivers. They may experience feelings of sadness, helplessness, and frustration as they witness their loved one's pain and difficulties. The caregiver may also feel a sense of responsibility for their loved one's well-being, leading to feelings of guilt or inadequacy if they are unable to alleviate their loved one's suffering (Prunty & Foli, 2019). Moreover, Informal

caregivers of individuals with depression face emotional challenges as they juggle multiple roles. They may have professional commitments as workers or students, family responsibilities as children or parents, and the need to support their partners. Additionally, they may have personal goals and desires. Balancing these responsibilities can be emotionally demanding, leading to stress and feelings of overwhelm. If this continues in the long run, it may contribute to burnout and a lower quality of life. Overall, the demanding nature of caregiving, the complexity of depression, lack of awareness in society, the emotional toll of witnessing a loved one's struggle, and multiple roles contribute to the difficulties faced by informal caregivers. The research conducted by Lu et al (2019) supports the notion that caregivers experience emotions of isolation, mental fatigue, and a sense of being "trapped".

Depression is a complex mental health condition that can affect a person's ability to express themselves verbally. As a result, individuals with depression may withdraw from social interactions Kupferberg & Hasler (2023), find it challenging to articulate their emotions, or struggle to communicate their needs clearly. The lack of communication skills among informal caregivers can further complicate the situation. Informal caregivers may face challenges in understanding and interpreting the non-verbal cues and subtle changes in behaviour exhibited by individuals with depression. This can lead to miscommunication or misunderstandings, hindering the ability to provide appropriate support. Therefore, developing an evidence-based module that includes communication skills enhancement for informal caregivers of individuals with depression is essential (Lloyd et al., 2023). This module aims to enhance communication skills and deepen the understanding of depression, enabling caregivers to offer more meaningful support to their loved ones. This is supported by Jeyathevan et al (2019) who suggested a comprehensive support for caregivers including education, coping strategies, communication skills training, and counselling.

The role of a caregiver requires a significant commitment of time, energy, and resources to provide support and care to their loved ones. However, this dedication often comes at the expense of neglecting their own well-being and personal needs. The caregivers' dedication to caring for loved ones constrained their freedom and well-being as they prioritized that commitment over other aspects of their lives (Horrell et al., 2015). Caregivers may find themselves constantly prioritizing the needs of their family members, leaving little time and energy for self-care and attending to their own personal needs. The relentless focus on supporting their loved ones can result in increased stress, exhaustion, and a decline in their overall quality of life. Based on past research by Gérain & Zech (2019), the researchers discussed that appraisal refers to the caregivers' personal and subjective evaluation of their caregiving experience. It involves assessing the balance or imbalance between the demands and available resources, essentially weighing the various factors that influence their caregiving situation. Caregivers' unmet self-care needs primarily revolved around the negative impact of caregiving on their lifestyle, encompassing challenges in reducing stress, managing personal health, balancing work and activities, taking breaks, accessing support services information, and addressing fears about physical or mental deterioration (Denham et al., 2020). The guilt experienced by informal caregivers can be a significant factor that leads to the neglect of their own self-needs. In many cultures, including Malaysia, there is a societal expectation that prioritizing others over oneself is seen as noble and praiseworthy. This cultural belief may contribute to caregivers feeling obligated to sacrifice their own well-being for the sake of their family members. The guilt stems from the perception that taking care of oneself or addressing personal needs is selfish or neglectful towards the depressed family member. It is important for caregivers to acknowledge their own needs and seek support,

when necessary, as their well-being ultimately contributes to the overall well-being of both themselves and their loved ones.

In Asian culture, there are often strong cultural norms and beliefs surrounding mental health that contribute to the taboo surrounding the topic. Mental health issues are often considered private matters that should be kept within the family. This contributed to the lack of open dialogue and awareness about mental health contributes to the perpetuation of stigma. Mental health issues are often viewed as a personal weakness or something to be ashamed of Zhang et al (2019), rather than as legitimate medical conditions requiring treatment and support. This limited understanding leads to the marginalization of individuals with mental health issues and a lack of access to appropriate care. Addressing stigma and increasing social support for informal caregivers is crucial for their well-being. Creating awareness and understanding about mental health issues, fostering a supportive and inclusive environment, and providing access to resources and support networks are essential steps in alleviating the negative impact of stigma and social isolation on caregivers. By promoting acceptance, empathy, and support, caregivers can receive the understanding and assistance they need, leading to improved well-being and better care for their loved ones with depression. Riches et al (2022) discussed the significant implications for policymakers and support organizations, highlighting the importance of considering the needs of the entire family, not just the care-recipient.

Conclusion

This study provided a comprehensive and in-depth understanding of the personal experiences and psychological needs of informal caregivers of individuals with depression through a thematic approach. To mitigate the personal experiences and psychological needs of the caregivers, it is crucial for informal caregivers to receive education and training on depression, including Awareness & Knowledge of Changes in Behaviour and Personality of Family Members with Depression, Emotional Difficulties, Communication Skills, Balancing Personal Needs and the Needs of Family Members with Depression, and Stigma and Social Support. It's important to acknowledge that due to the nature of qualitative research, the sample size was limited. However, the findings can serve as a valuable reference for future interventions in burnout prevention among caregivers and may inspire further in-depth research. The limited research on this population highlights the importance of building upon these findings to advance knowledge in this field.

Building on this knowledge gap, this research significantly contributes to existing knowledge by extending Gérain & Zech's (2019) Informal Caregiving Integrative Model (ICIM) to specifically address the experiences and psychological needs of informal caregivers of individuals with depression. By applying ICIM in this context, the study highlights unique stressors such as lack of awareness about depression, emotional difficulties, communication challenges, and the impact of cultural stigma, thereby broadening the model's applicability. The focus on Malaysian caregivers provides valuable insights into the specific cultural and social dynamics influencing caregiver burnout. The research emphasizes the urgent need for specifically tailored education, training, and support systems to enhance caregivers' well-being and effectiveness. By taking cultural norms and societal expectations into account, the study offers a nuanced understanding that underscores the importance of recognizing and addressing the diverse needs of informal caregivers across different settings.

Acknowledgement

I would like to extend my heartfelt gratitude to Dr. Rozainee Khairudin for her unwavering support, mentorship, and invaluable advice throughout my research journey. Her faith in me and continuous encouragement made this work possible. I am also deeply thankful to Sir Akif Basri, Dr. Nasrudin Subhi and Dr. Daniella Maryam Mohamed Mokhtar for their guidance and insightful contributions to my research. Additionally, I am grateful to my dear friends, Noor Farhana Binti Noor Azman and Aisyah Rosli, for their unconditional support, encouragement, and constructive feedback along the way.

References

- Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs, 18*(2), 182–188.
- Balkaran, B. L., Jaffe, D. H., Umuhire, D., Rive, B., & Milz, R. (2021). Self-reported burden of caregiver of adults with depression: a cross-sectional study in five Western European countries. *BMC Psychiatry, 21*(1).
- Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of informal caregiving on caregiver employment, health, and family. *Journal of Population Ageing, 8*(3), 113–145.
- Bracke, P., Delaruelle, K., & Verhaeghe, M. (2019). Dominant Cultural and personal stigma Beliefs and the Utilization of Mental Health Services: A Cross-National Comparison. *Frontiers in Sociology, 4*.
- Denham, A. M. J., Wynne, O., Baker, A., Spratt, N., Turner, A., Magin, P., Palazzi, K., & Bonevski, B. (2020). An online survey of informal caregivers' unmet needs and associated factors. *PLOS ONE, 15*(12), e0243502.
- Faronbi, J. O., Faronbi, G. O., Ayamolowo, S. J., & Olaogun, A. A. (2019). Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Archives of Gerontology and Geriatrics, 82*, 8–14.
- Fugard, A. J. B., & Potts, H. W. W. (2015). Supporting thinking on sample sizes for thematic analyses: a quantitative tool. *International Journal of Social Research Methodology, 18*(6), 669–684.
- Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in Psychology, 10*.
- Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. *Health Psychology, 34*(4), 339–348.
- Institute for Public Health 2020. National Health and Morbidity Survey (NHMS) 2019: Non-communicable diseases, healthcare demand, and health literacy—Key Findings
- Jeyathevan, G., Cameron, J. I., Craven, B. C., Munce, S., & Jaglal, S. (2019). Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. *BMC Neurology, 19*(1).
- Kindt, S., Vansteenkiste, M., Loeys, T., Caño, A., Lauwerier, E., Verhofstadt, L., & Goubert, L. (2015). When Is Helping your Partner with Chronic Pain a Burden? The Relation Between Helping Motivation and Personal and Relational Functioning. *Pain Medicine, 16*(9), 1732–1744.
- Konerding, U., Bowen, T., Forte, P., Karampli, E., Malmström, T., Pavi, E., Torkki, P., & Graessel, E. (2016). Investigating burden of informal caregivers in England, Finland and Greece: an analysis with the short form of the Burden Scale for Family Caregivers (BSFC-s). *Ageing & Mental Health, 22*(2), 280–287.

- Kupferberg, A., & Hasler, G. (2023). The social cost of depression: Investigating the impact of impaired social emotion regulation, social cognition, and interpersonal behavior on social functioning. *Journal of Affective Disorders Reports*, 14, 100631.
- Lehtonen, T. (2022). Belief in Karma: The Belief-Inducing Power of a Collection of Ideas and Practices with a Long History. *Religions*, 14(1), 52.
- Lloyd, A., Broadbent, A., Brooks, E., Bulsara, K., Donoghue, K., Saijaf, R., Sampson, K. N., Thomson, A., Fearon, P., & Lawrence, P. J. (2023). The impact of family interventions on communication in the context of anxiety and depression in those aged 14–24 years: systematic review of randomised control trials. *BJPsych Open*, 9(5).
- Lu, Q., Mårtensson, J., Zhao, Y., & Johansson, L. (2019). Living on the edge: Family caregivers' experiences of caring for post-stroke family members in China: A qualitative study. *International Journal of Nursing Studies*, 94, 1–8.
- Martínez, J. P., Méndez, I., Esteban, C. R., Fernández-Sogorb, A., & García-Fernández, J. M. (2020). Profiles of burnout, coping strategies and depressive symptomatology. *Frontiers in Psychology*, 11.
- Misiolek-Marín, A., Soto-Rubio, A., Misiołek, H., & Gil-Monte, P. R. (2020). Influence of burnout and feelings of guilt on depression and health in anesthesiologists. *International Journal of Environmental Research and Public Health*, 17(24), 9267.
- Prunty, M. M., & Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A concept analysis. *International Journal of Older People Nursing*, 14(2).
- Riches, V., O'Brien, P., Manokara, V., & Mueller, A. (2022). A study of caregiver support services: Perspectives of family caregivers of persons with intellectual disabilities in Singapore. *Journal of Policy and Practice in Intellectual Disabilities*, 20(1), 117–131.
- Zhang, Z., Sun, K., Jatchavala, C., Koh, J., Chia, Y., Bose, J., Li, Z., Tan, W., Wang, S., Chu, W., Wang, J., Tran, B., & Ho, R. (2019). Overview of Stigma against Psychiatric Illnesses and Advancements of Anti-Stigma Activities in Six Asian Societies. *International Journal of Environmental Research and Public Health/International Journal of Environmental Research and Public Health*, 17(1), 280.
- Zhou, Z., Wang, Y., Feng, P., Li, T., Tebes, J. K., Luan, R., & Yu, Y. (2021). Associations of caregiving knowledge and skills with caregiver Burden, Psychological Well-Being, and coping styles among primary family caregivers of people living with schizophrenia in China. *Frontiers in Psychiatry*, 12.