



Faculty of Cognitive Sciences and Human Development

**GRIEF IN ADOLESCENCE: THE PSYCHOLOGICAL WELL-BEING OF
UNIVERSITY STUDENTS FOLLOWING PARENTAL DEATH DUE TO LONG-
TERM ILLNESS**

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UNIVERSITY STUDENTS FOLLOWING PARENTAL DEATH DUE TO LONG-
TERM ILLNESS**

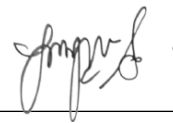
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ABSTRACT

This study aimed to understand the grief experiences of adolescents going through parental death and how it affects their well-being in aspects of emotionally and physically. Through in-depth interviews with 8 UNIMAS students who had lost their parents from long-term illness during adolescence, it was found that grief takes forms in the lack of grief expression, emotional, physical, and financial struggle, as well as difficulty in keeping faith in their religion. The ongoing mental development during adolescence has also become a main finding in explaining the complexity of grief and how parental death during this phase affects the participants' mental growth towards adulthood. Theories of the PERMA Model of Well-being and Kübler-Ross 5 Stages of Grief are used to explain the diverse grief experiences and the coping strategies utilised by the adolescents. Despite its devastating effects, experiencing a parental death can be a catalyst for positive growth in life, particularly in family relationships and motivation. Therefore, this study hopes to offer insight into understanding adolescents' grief towards the public, especially parents and professionals so that appropriate support that caters to adolescents' needs can be provided.

ABSTRAK

Kajian ini bertujuan untuk memahami pengalaman remaja dalam menghadapi kedukaan selepas kematian ibu atau bapa akibat penyakit jangka panjang dan bagaimana ia mempengaruhi kesejahteraan mereka dari aspek emosi dan fizikal. Melalui temubual secara mendalam bersama 8 orang pelajar UNIMAS yang telah kehilangan ibu atau bapa akibat penyakit jangka panjang ketika remaja, didapati bahawa kedukaan wujud dalam bentuk kurangnya komunikasi tentang perasaan sedih tersebut, bergelut secara emosi, fizikal, dan kewangan, serta mempersoalkan kepercayaan agama mereka. Perkembangan mental yang sedang berjalan ketika fasa remaja juga merupakan dapatan kajian yang penting dalam menjelaskan betapa kompleksnya kedukaan yang dialami para remaja tersebut, begitu juga bagaimana ia mempengaruhi pertumbuhan mental remaja menuju fasa dewasa. Teori seperti PERMA Model of Well-being dan Kübler-Ross 5 Stages of Grief digunapakai untuk menjelaskan kepelbagaian pengalaman kedukaan yang dialami oleh remaja serta strategi untuk mengatasinya. Walaupun kehilangan seorang ibu atau bapa memiliki banyak impak negatifnya, ia juga dapat menjadi pemangkin kepada pertumbuhan yang lebih positif dalam hidup, terutamanya dalam hubungan kekeluargaan dan motivasi. Oleh itu, diharapkan kajian ini dapat memberi pandangan kepada orang awam dalam memahami kedukaan remaja, terutama sekali kepada ibu bapa dan para pakar supaya sokongan yang sesuai dan selari dengan keperluan remaja dapat disediakan.

CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter contains the background study, problem statement, research objectives, research questions, research framework, the significance of the study, definition of terms, and limitations of the study.

1.1 Background of Study

A study by Agnis Sombuling et al. (2012) suggested that one out of four life events that trigger Malaysian adolescents' sadness is death and loss. Agnis Sombuling et al. (2012) specifically mentioned that the death or loss of parents affects adolescents' emotions negatively, with a frequency of 70 out of 994 undergraduate students (42.4%). The result placed the second highest in the 'Life events that trigger emotion sadness: Death and Loss' category while 'death or loss of a loved one' scored the highest.

Adolescence is characterised by a particular brain development in which neurological parts' final growth occurs. Significantly, the development of the frontal lobe is involved in problem-solving, language, memory, spontaneity, judgment, impulse control, and social and sexual behaviour (Farella Guzzo & Gobbi, 2021). However, adolescents' social and emotional maturity is not fully developed for them to integrate and process loss, grief, and trauma (Adebäck et al., 2022). Hence, the death of a parent during adolescence is a major risk factor for developing and maintaining both internalizing (e.g., depression and anxiety) and externalizing (e.g., aggression and substance abuse) mental health problems (Tafà et al., 2018). Not only that, but early parental loss could also lead to socioeconomic problems, especially if

the deceased parent is the main breadwinner of the family (Adebäck et al., 2022), which can lead to experiencing difficulties in the workplace, school dropout or diminishing educational aspirations, and struggling with interpersonal and intimate bonds (Tafà et al., 2018; Weinstock et al., 2021).

Parents suffering from long-term illnesses may hinder communication about it with their children because parents believe their children are too young to understand. Being overwhelmed by their own suffering and fear of failing their role as parents, and the anticipatory grief of missing their child growing into adulthood are also some of the reasons parents choose not to tell their children about their health conditions (Dalton et al., 2019). Dalton et al. (2019) also found that adolescents (11-15 years old) choose to hide their grief of potentially losing their parents because they fear bringing the stress and upset their parents, along with guilt and selfishness of burdening their parents with their own feelings and not being able to prevent the death (Adebäck et al., 2022). Not only the suffering parents go through anticipatory grief but also their children, in which they anticipate their parent's death and therefore, are stuck in a denial state and choose to keep their feelings to themselves (Dalton et al., 2019).

The grief that takes part during and after the death of a parent relies on the deep connection between the surviving parent and other family members. Communication about the death and the emotional aspects, as well as socioeconomic status (especially if the deceased parent is the main breadwinner of the family), can provide closure and better support to all the family members to deal with life after the loss (Birgisdóttir et al., 2023).

Adolescence is a period of transitioning from childhood to adulthood in which adolescents still require their parents' support in terms of emotional and instrumental (Adebäck et al., 2022). Therefore, they may hide their grief so as not to want to be a burden to their other family members who are emotionally struggling at the time of the loss. Worden (2018, p. 41-50) categorised grief and mourning into four tasks: 1. To accept the reality of the loss, 2. To process the pain of grief, 3. To adjust to a world without the deceased, and 4. To find a way to remember the deceased while embarking on the rest of one's journey through life. Adolescents' development makes grieving an intricate phenomenon for their bodies and emotions. Hence, this study will investigate the complexity of grief through the impact of parental death due to long-term illness on adolescents' development and psychological well-being, the risk factors, as well as the coping strategies needed.

1.2 Problem Statement

The impact of grief in adolescents has been seen to cause negative behavioural reactions (Tafà et al., 2018). This can result from the lack of grief communication within the family which causes the absence of support as reported by Dalton et al. (2019). Studies by Li et al. (2023) and Dalton et al. (2019) have been done on the importance of communication between parents and their children about the possible death from long-term illness. Specifically, Li et al. (2023) touches on Chinese culture and how it affects grief communication within the family. Tang & Li (2019) also found that the Chinese tend to suppress their emotions as a form of defense of their self-image. Additionally, Tang & Li (2019) found that Chinese college students disregard family support and prefer independence, while also heavily influenced by Chinese cultural values that believe death is a taboo topic. As a result, their expression of grief is hindered.

According to Dalton et al. (2019), parents choose to not tell their children such information as it might cause fear and anxiety to their children. Thus, it hinders adolescents from preparing themselves to deal with the loss and is often filled with guilt and regret for not being able to stop the death. There have been some attempts in research to show how therapy and counselling work as coping strategies for grieving adolescents such as studies done by Boelen et al. (2021) on 'CBT for prolonged grief in children and adolescents' and Hill et al. (2019) on 'Multidimensional Grief Therapy'.

Besides, a lot of data are a combination of children and adolescents or adolescents and adults. There is a difference in the neurodevelopmental processes of adolescence as compared to the two phases. Therefore, the combination of results may provide bias that leans towards only one part of the life period, as adolescence is still a separate phase from childhood and

adulthood (Farella Guzzo & Gobbi, 2021). Larsen et al. (2021) stated that losing a parent at an early age of 0-18 years old increased children's vulnerability and put them at risk for short- and long-term effects. Notably, adolescents (aged 10-19) have been found at higher risk of mental health problems, low self-esteem, and low life satisfaction. Not only that, but bereavement may also drive them towards academic difficulties, and disruption in developmental, occupational, and social tasks (Larsen et al., 2021).

In doing this research, most studies found are looking into the effects of bereavement and grief on adolescents and not the grieving process itself. Farella Guzzo & Gobbi (2021) questioned the 'parentification' of adolescents after the death of a parent, in which the adolescents are turned into surrogate parents and take care of the family. This resulted in the inability of adolescents to separate from their main caregivers and have freedom into adulthood. Consequently, interventions or professional help would go to waste if the grieving process were not understood accurately. In addition, a lot of studies are done quantitatively with predetermined questionnaires. This obstructs the details required to understand the experiences of adolescents during their grieving period.

Despite the obvious negative impacts of grieving on adolescents, less is still known about the positive behavioural reactions in grieving adolescents (coming out of the crisis). A study suggested that loss increases empathy and boosts appreciation for life (Andriessen et al., 2018). Besides, if the parent who passed away was abusive, there may also be a benefit to their passing. Looking into the positive impacts can provide insights that grief and death are not all unfortunates.

Therefore, the aim of this research is to better understand the grief experiences of university students losing a parent during adolescence and how it impacted their growth towards adulthood, either positively or negatively. Qualitative methods will be used to gain in-

depth insight into the risk factors and effects of parental death on the psychological well-being of university students, as well as look at effective coping strategies for grief.

1.3 Research Objectives

1.3.1 General Objective

To explore the psychological experiences of grief in adolescents following parental death due to long-term illness.

1.3.2 Specific Objectives

1.3.2.1 To investigate the risk factors of grief in adolescents after parental death due to long-term illness.

1.3.2.2 To study the effects of parental death on adolescents' well-being and throughout their adulthood.

1.3.2.3 To explore the coping strategies for grief in adolescents after parental death due to long-term illness.

1.4 Research Questions

1.4.1 What are the risk factors of grief in adolescents after parental death due to long-term illness?

1.4.2 What are the effects of parental death on adolescent well-being?

1.4.3 What are the coping strategies adopted by adolescents dealing with grief after the death of a parent?

1.5 Research Framework

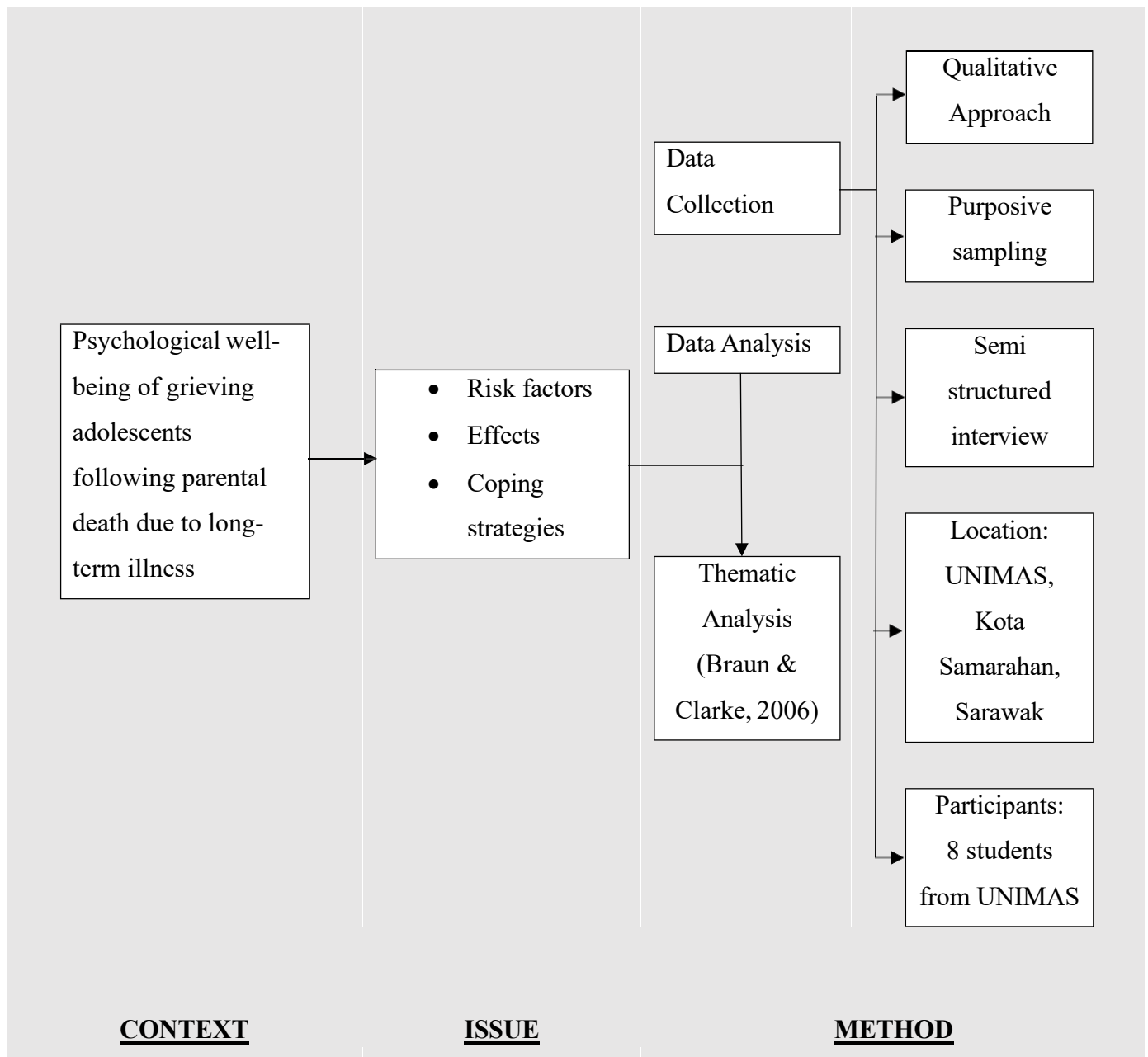


Figure 1: Research Framework

1.6 Significance of Study

This study seeks to explore the experiences of adolescents dealing with the death of a parent in Malaysia, specifically in Sarawak. This is because the emotional need for adolescents is often neglected by their other family members, especially if they have younger siblings. There seems to be a need for middle- and late-adolescents to be emotionally mature and accept the death with open heart as oppose to younger children. However, adolescents of any age still need support, especially from their parents as they are still developing themselves into adulthood. This neglect may cause difficulty in adolescents to grieve healthily. Thus, adolescents may find themselves trapped in risk-taking activities such as alcoholism, drugs, and running away from home.

There is a limited number of academic works involving grieving adolescents for the death of a parent as most focus on children and adults. Moreover, different people experience and express grief differently. Thus, this study can be used to understand the challenges faced by adolescents in coping with grief. This is because new challenges can arise as time goes by and therefore with continuous research, the coping strategies and interventions can be constantly updated.

With this research, it is hoped that adolescents will be aware of the risk factors of grief and obtain increased knowledge on how to deal with grief healthily. The data collected in this study can be used to increase awareness of grief communication and highlight the significance it plays within the bereaved family. Not only that, this study should eliminate the cultural taboo in Malaysia of not expressing grief openly as the knowledge of grief is being brought to light. Besides, it can be used as a guideline in providing support to grieving adolescents, whether by professionals or parents. Early interventions such as counseling and group therapy are crucial in reducing the impact of prolonged grief in adolescents.

1.7 Definition of Terms

1.7.1 Grief

Conceptual definition:

Jacob (1993) understood grief as a rather normal and pervasive but individualised feeling that touches the aspects of emotional, physical, social, and spiritual due to the loss of a significant other. Weinstock et al. (2021) described grief as an emotional energy undergone by human beings subsequent to the death of someone or something that is dear to them.

Operational definition:

In this study, grief is defined as the feeling of sadness and sorrow in adolescents after the death of a parent to a long-term illness.

1.7.2 Risk factors

Conceptual definition:

Substance Abuse and Mental Health Services Administration (2019) defined risk factors as characteristics at the level of physiological, biological, family, society, or culture that escalate the possibilities of negative consequences. American Mental Wellness Association (2019) explained risk factors as something that aid in generating problems.

Operational definition:

In this study, risk factors include the role of individual factors: e.g., coping skills and social support, family factors: e.g., quality of communication and support from surviving parent, and cultural factors: e.g., religious beliefs and bereavement rituals.

1.7.3 Adolescents

Conceptual definition:

World Health Organization (2023) better known as WHO defined adolescence as a period between childhood and adulthood, with adolescents categorised into people of age 10-19 years old. Sawyer et al. (2018) defined adolescence into 3 categories 10-15 years old as early adolescence, 13-20 years old as teenagers or middle adolescence, and 15-20 years old as older or late adolescence.

Operational definition:

In this study, adolescents are categorised into people of the age 10-20 years old.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

In this chapter, the researcher discusses on the previous research related to the psychological well-being of grieving adolescents globally and in Malaysia perspectives, the struggles faced following parental death due to long-term illness, and the coping strategies of the grieving adolescents. Besides, the theory of positive psychology will also be discussed.

2.1 Grief, Loss, and Bereavement

According to American Psychological Association (2018), bereavement is a condition of having lost a loved one to death. Grieving individuals are described as bereaved. A literature review by Lytje & Dyregrov (2019) on the psychosocial and childhood bereavement described a parent's death during childhood changed a safe and steady world into a frightening and strange world filled with uncertainties. There is also a growing consensus on the consequences of loss in every aspects of life such as psychological (reactions such as anger, fear, guilt, dysphoria, and regression), physical (loss of appetite, headaches, muscle pain, and concentration difficulties), and social towards bereaved children (Lytje & Dyregrov, 2019). Generally, the social consequence of childhood bereavement is losing the breadwinner of the family. Thus, they could not afford to live a life before the loss and may have to depend on external financial support, especially in low- and middle-income families.

Defined as the intense emotional distress arising from a significant loss, grief manifests in a multitude of ways, including physiological turmoil, separation anxiety, cognitive disorientation, persistent yearning, fixation on the past, and trepidation regarding the future.

While primarily associated with the passing of a cherished individual, grief can also embrace regrets for deeds undone, remorse for past actions, and sorrow for personal setbacks (American Psychological Association, 2020). In the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition Text Revision (DSM-5-TR), grief manifests as prolonged grief disorder that can be diagnosed only after at least 12 months (6 months in children and adolescents) have elapsed since the death of someone with whom the bereaved had a close relationship with (Criterion A), experience intense yearning and preoccupation on the deceased (Criterion B), with the addition of 3 out of 8 symptoms of identity disruption, marked sense of disbelief about the death, avoidance, intense emotional pain, difficulties moving on, emotional numbness, feeling that life is meaningless, and intense loneliness after the death occurring for at least one month (Criterion C), causing distress or disability in social, occupational, or other important areas of functioning (Criterion D), the bereavement reaction exceed cultural and contextual norms (Criterion E), and symptoms are not better explained by another mental disorder (Criterion F) (American Psychiatric Association , 2022).

Çakar (2020) categorised losses into 2 types: primary losses (death, divorce/separation, loss of work, moving, etc.) and secondary losses (loss of relationships, friendship, security, identity, finance, stability, role, support system, hopes, dreams, expectations, etc.). It should also be taken into account the significance of both these types of loss, both are real and cause pain which brings grief to everyone going through them (Çakar, 2020). Grief is understood to be a universal response, surpassing limitations imposed by culture, time, and geography experienced by everyone but is also distinct to individuals (Subianto & Winardi, 2023).

A study by Lundorff et al. (2020) on prolonged grief disorder between genders found that men exhibited a pattern of prolonged grief, with intense symptoms that gradually diminished around six months after the loss. In contrast, women experienced a delayed grief response, with symptoms initially appearing milder but gradually intensifying over time. On

the other hand, a study by Stelzer et al. (2019) found that gender has little influence on the grieving process; where both men and women are willing to talk about their grief openly. The researcher suggested that this finding may have been influenced by individuals' personalities and beliefs. This is because, participants were comprised of individuals who voluntarily participated in the study and therefore, created an understanding that they are comfortable and motivated to discuss their experience with the loss. Nonetheless, the researcher proposed the importance of situational context where, as gender roles are exceptionally notable and behaviour is more gender stereotyped, there may be a significant difference in the grief responses.

2.2 Adolescents' Loss and Grief

Losing a loved one at any age is devastating (Ferow, 2019). However, Adebäck et al. (2022) considered loss during childhood and adolescence to be very impactful and is considered to be the most stressful event in one's life. This experience brings about potential developmentally and psychologically disruptive challenges (Zulliger, 2023). Alvis et al. (2022) described that grief during childhood and adolescence differs from adulthood because they experience difficulties in accepting the loss, extreme yearning, anger, and a sense that life is meaningless.

According to Larsen & Luna (2018), the critical period for the development of higher-order cognition occurs during adolescence. It marks the transition from adolescence to adulthood. A period called the critical period is the intricate biological mechanism that governs the accelerated growth of neurobiological and cognitive capacities throughout adolescence and their eventual stabilisation in adulthood. Larsen & Luna (2018) suggested that adolescents' and adults' cognitive performances still differ despite having the same core cognitive functions

since early development. This is because the processes that support reliable cognitive performances as adults are still developing. As a result, adolescents went through higher error rates, varied in their actions, and had slower response latency which is reflected in their indecisiveness.

As cognitive functions are still actively developing, it puts adolescents at risk for abnormal development when forced to undergo abnormal experiences such as excessive amounts of stress and trauma. This is due to the fact that there is a strong relationship between experience and neurobiology in which disruptions to normal experience would contribute to abnormal outcomes. This supports the fact that psychiatric disorders such as depression, anxiety, substance abuse, and post-traumatic stress disorder (PTSD) often manifest during adolescence (Larsen & Luna, 2018).

Prolonged or elevated stress hormone levels have a significant impact on the adaptability of the prefrontal cortex (PFC) circuitry and PFC-related functions such as working memory and flexibility. Considering the ongoing developmental processes in the adolescent PFC and the heightened stress hormone response during adolescence, stressful experiences exert a particularly potent influence during this stage of life (Larsen & Luna, 2018).

Although experience and neurobiology are interrelated across all stages of development, the brain's hierarchical organization suggests that early developmental disruptions in sensory processing can have a ripple effect on the development of higher-order cognitive functions. Disruptions to sensory systems early in life can compromise the quality of sensory information reaching higher-level brain regions, such as the prefrontal cortex (PFC), which is responsible for integrating sensory inputs. This can, in turn, negatively impact cognitive development later in life (Larsen & Luna, 2018).

A study by Asgari & Naghavi (2019) discovered that adolescents who lost their fathers due to sudden death faced initial confusion over the notion of death. This resulted in increased suffering as the death was rather unexpected and losing someone when they were still young required complex cognitive processes that simultaneously affected their behaviour. A participant in the study done by Asgari & Naghavi (2019) mentioned that shock and denial are the primary emotions encountered, followed by disbelief and distress. Not only that, other participants described feelings of anger, sadness, stress, loneliness, and even hatred towards themselves, other people, and their own life. This hatred later manifested in the form of wavering faith in their own religion and some of the participants refused to believe in God for taking the life of their loved ones.

The impact of the death was also shown through abnormal behaviours such as aggression and shutting down communication between the school and society. One participant explained that having others know about the loss of her father would make the grieving process worse as other people would sympathise with her (Asgari & Naghavi, 2019).

Cafferky et al. (2018) in a study conducted on parental terminal illness (PTI) and death found that adolescents observing a parent's deteriorating health caused feelings of confusion, anxiety, and distress especially as there are changes in their bodies and the way they look, in which a participant described her ill father as 'he wasn't really himself'. The change was so significant that it altered the parent-child relationship. There is a realisation that the illness caused the parent could not be relied on for security and comfort. As a consequence, the adolescent (child) tried to separate their parent from their illness to rationalise the shift in the relationship dynamic which caused grief preceding bereavement.

As mentioned by Larsen & Luna (2018) on adolescents' ongoing cognitive developmental level, participants revealed struggling to fully grasp their parent's terminal

illness as they believed at that time during adolescence, their understanding was limited (Cafferky et al., 2018).

2.3 Adolescents' Loss and Grief in Asia and Malaysia

A qualitative study by Li et al. (2023) in China found that almost all participants which were made up of adolescents and young adults, never shared grief with other family members. This was highly caused by the family-centered society in China where bereavement and grief are treated as taboo. Three themes emerged from the study which are 'hiding emotions', 'pretending no grief at all after the loss', and 'keeping grief secret as a family rule'. One participant had to hold back tears watching his other family members cried reminded him that at least one person should be sober for funeral responsibility. It was not until three days later that the participant was crying in his university room and finally grieved for his deceased father.

Besides, another participant had to go through anticipatory grief at 16 when she discovered her father had to seek medical treatment away from home for liver cirrhosis. The participant and her younger sister went through two months before knowing about their father's death. The situation was very traumatising that the participant decided to withdraw from any grief communication within her family. This is because she had to keep her mother's and younger sister's emotions in check so as not to trigger the 'unpleasant feelings' after the death.

Lastly, the 'grieving rules' in certain families in China were very emphasised that one participant suffered from facial paralysis as a result of emotional distress. The participant mentioned that she never discussed the impact of her father's death with her family members and was even told not to mention the word 'father' as it might trigger grief in the family. She was still young during her father's death and had no idea of the reason for the designated rule. To avoid provoking her mother's anger, the participant followed the rule obediently even when

she felt sad. It was later when she went to college and studied psychology that she tried to break the family rule by disclosing her grief to her family members. Despite that, her attempt failed and she ended up never sharing her grief again. Another victim of the ‘not disclosing grief as a family rule’ was a participant who had to keep her fatherless identity a secret. This is due to the fact that she was conditioned to never mention her father and lied about her family status. The participant made herself believe that her father has retired and was told not to tell anything to anyone in school.

The researchers proposed that not disclosing grief was a way to protect the family, especially the surviving parents. The participants would also have to take the parental roles as their surviving parents grieve for their partners, taking responsibility by taking care of their siblings and dealing with funeral arrangements all during and after the period of the loss and until the grief subsided to avoid putting the load on other family members.

According to Tang & Li (2019), they indicated that one of the most traumatic events faced by a college student is the loss of a parent to cancer. A qualitative study was done at a local university in China with 18 volunteered college students aged from 18 to 21 years old. The study found 4 major themes. The first one is ‘facing huge life changes’ in which the participants struggled with the emotional impact of loss, exhibiting reactions such as denial, avoidance, and sudden life disruptions. They identified longing and sadness as the most significant obstacles they faced. Despite these challenges, most participants reported a notable reduction in depressive symptoms. However, many still experience negative reactions to birthdays, holidays, and death anniversaries. A relatively small number of participants were aware of available bereavement support services.

The next theme circulated around ‘experiencing loss and suffering’ which include experiences such as grappling with the acceptance of death, dealing with the weight of

perceived filial obligations towards a departed parent with cancer, and enduring the ache of longing were prevalent emotions among college students. For most students who experienced a typical lifespan, the loss of a beloved relative was an unavoidable reality. Students viewed the experiences of loss and suffering as fundamental to the human condition.

Besides, Tang & Li (2019) also observed on the ‘challenges and coping strategies for facing parental death’. Participants went through feelings of isolation, a lack of practical (i.e. money) and emotional support, and difficulty coping with grief. Social support can be found in various forms, such as through family; but it was also still very limited as some of the participants’ families were living in different areas, friends and support groups. Additionally, individuals employ different coping strategies to navigate the challenges of parental death such as finding new meaningful roles to rekindle their passion and pour love into another valued pursuit. Those roles include being involved in self-help groups and putting more effort into study and personal achievements.

Lastly, the theme of ‘re-interpreting death’ propelled the participants on a quest to comprehend the meaning of death by rationalising death and believing it is inevitable, and seeking to reconcile their grief through a process of meaning reconstruction through the philosophy of Confucianism: Confucians uphold the belief in a transcendent realm and the soul's continued existence, extending the principles of filial piety to honour ancestors. Upon a parent's passing, children are expected to fulfill their filial duties by providing care and respect. In Confucian philosophy, a meaningful death is one that upholds Confucian virtues (Tang & Li, 2019). This journey involved interpreting death through personal symbolism, rationalizing its inevitability, establishing a personal understanding of its significance, and embracing the transformative power of loss and growth.

Pacaol (2021) in a descriptive case study on a Filipino senior high school discovered the significance of developmental level in processing grief. The participant reported having the knowledge and information that his parents passed away. However, he was not sensitive enough to express his grief in a way that he was nonchalant about it, although he was aware of his own loss. This is because the cognitive limitations of children may make it difficult for them to fully appreciate the profound and multifaceted concept of death. Growing up and entering adolescence, the participant acquired sufficient realisations of his condition and the absence of both his parents evoked a torrent of emotional anguish in his mind. The participant went through maturation and acceptance of the death by choosing to be a teenager rather than going back as a child (if possible) because being a teenager would give him 'more realisations and become knowledgeable'.

As a matter of grief communication, the participant chose to not disclose his grief on his own choice. While time may aid in comprehending and accepting death, the emotional anguish and enduring yearning experienced by surviving offspring and family members remained a critical concern. The need for unwavering emotional and moral support, often sought from parental care and companionship, was particularly evident. Despite seemingly overcoming the issue of acceptance in childhood, it resurfaced in response to certain triggers. Additionally, the participant struggled with envy towards the perceived completeness of other families around them (Pacaol, 2021).

Overall, adolescents' experience in grieving and bereavement in Asia is deeply rooted in the taboo of not disclosing and communicating about loss and grief. As a result, this can be detrimental to the psychological health of developing adolescents and may impact their growth negatively.

In the context of Malaysia, Redican et al. (2023) discovered the relationship between potentially traumatic events (PTEs) and their associations with post-traumatic stress disorder (PTSD). The researchers found that out of 469 Malaysian adolescent participants, 143 participants described the 'death of someone close' as PTEs, alongside other PTEs such as serious accidents, threats of violence or bullying, and physical assault. The result supported the researchers' claim that the death of a loved one has been shown to impact a wide range of PTEs. The researchers also found that participants with the 'death of someone close' as their PTEs are at moderate risk of suffering from PTSD.

In another study on 'stressful life events and depressive symptoms among adolescents in Malaysia' by Wong et al. (2020), parental loss is categorised as a negative life event and is one of the major life stressors that embodies traumatic experiences. When faced with the stated overwhelming stressor, individuals are in jeopardy of experiencing intense mental distress, potentially pushing them into or deepening depressive episodes, with a greater risk of substance abuse and dependence (Wong et al., 2020). Wong et al. (2020) found that individuals with high levels of stressful life events acquire the probability of suffering from extended maladaptive cognitive schema. Consecutively, they are more susceptible to depression.

Jasni et al. (2022) highlighted that the death of a parent or parents could lead to homelessness among teenagers in Malaysia. Aside from losing their parents who are their main support for their emotional and materialistic needs, they also have no experience living without their parents. Hence, they have to deal with life on their own. The non-existent of a house to protect them and money to provide for their daily needs, these teenagers are reported to become beggars on the street, and some resorted to stealing and drug dealing (Jasni et al., 2022).

2.4 The Experiences of going through Predeath Grief (PDG)

Liew et al. (2017) in a study done on predeath grief (PDG) in multiethnic Asian families (mostly consisting of Chinese and Malay) caregivers of persons with dementia (PWD) described the mourning process of PWD caregivers as unique whereby despite their physical presence, the PWD's emotional withdrawal creates a sense of loss and anticipation of the grieving process that will accompany their physical passing. The result discovered that 86% of caregivers reported average to high levels of PDG. The questionnaire discovered that a lot of the caregivers felt like they needed to sacrifice by giving up on their work and personal responsibilities, going through physical health decline from the stress of caregiving, and the inability to have freedom and personal time. However, the caregivers also reported feeling profound sadness and longing for the PWD, and even expressed anger and feeling powerless as the disease was trying to take their loved ones. Those negative feelings and thoughts led most of the caregivers to experience insomnia, anxiety, and severe depression.

Another study by Breen et al. (2019) took place among caregivers of persons receiving palliative care for cancer. The study reported a significant effect on caregivers' quality of life (QoL). The caregivers' QoL were significantly low during caring (predeath) but increased 3 to 4 months post-death. The researchers highlighted the importance of grief and bereavement services to caregivers as they found out that less than half of caregivers received adequate support from staff regarding coping or unanswered questions about the death, while nearly two-thirds were not asked about their emotional and psychological well-being, leaving them to navigate these challenges independently.

Holm et al. (2019) explored the fluctuations in grief, anxiety, depression, and overall well-being of family caregivers in the period leading up to and following the loss of a loved one in a palliative home care setting. The study followed caregivers of cancer, pulmonary, coronary, and neurological diseases patients. Caregivers reported health decreased predeath,

with a fluctuation of levels of anxiety and depression. Caregivers also reported feeling powerless and invisible but this receded post-death.

While these findings indicate that caregivers were generally well-prepared for the loss of their loved ones, as evidenced by a reduction in negative emotions and experiences following the death, it remains crucial to provide caregivers with ongoing support to manage symptoms of anxiety and depression and prioritize their own well-being.

2.5 Risk factors of Adolescents going through parental death

Birgisdóttir et al. (2023), in a study investigating family cohesion and its association with long-term health and well-being among teenagers after the death of a parent, found that 21.7% of the participants experienced poor family cohesion during the first year of the death. For this reason, the study reported that adolescents with poor family cohesion are susceptible to anxiety, depression, and increased sleeping problems. Another study by Birgisdóttir et al. (2019) that touches on family cohesion after losing a parent discovers that maternally bereaved teenagers had poor family cohesion that continued into young adulthood. Birgisdóttir et al. (2019) stated that although women are more likely to have healthy coping strategies compared to men, the gender of the surviving parent is less causative of family cohesion but rather of the role the surviving parent played within the family prior to the illness and the death. The findings added that poor family cohesion has a significant effect on female adolescents' well-being as they go through more emotional distress compared to male adolescents. This is because female adolescents are reported to be more emotionally vulnerable and more likely to internalise their problems as they need to take responsibility for their families (Birgisdóttir et al., 2019).

Based on a study on the 'impact of loss-related stressors on the psychological well-being of young adults coping with parental bereavement' by Lundberg et al. (2018), young

adults generally experienced diminished psychosocial well-being following parental loss from cancer. The majority of young adults were caught off guard by their parent's death, with a significant minority unaware of the impending loss. This unexpected bereavement led to widespread reports of poor psychosocial well-being, including low self-esteem, anxiety, depression, and dissatisfaction with life during the first year after their parent's passing. While the majority of parents received palliative care, which typically includes support for the family during the patient's illness, most young adults were unprepared for the suddenness of their parent's death. A significant number of them seemed unaware of the impending loss. This suggests that support groups for offspring with parents in palliative care should be enhanced to better prepare them for the possibility of their parent's death.

Another study by Tafà et al. (2018) discussed the influence of parental psychological difficulties and the emotional problems of children on their physical health. The study found that dissociation among offspring was the strongest predictor of physical health problems, even after accounting for factors such as gender and age. Both parental psychological problems and dissociation in youth contribute to physical health issues, but dissociation is the primary factor. This suggests that the trauma of losing a parent extends beyond the loss itself and affects the relationship with the surviving parent. The researchers, focusing on emotionally traumatic experiences in childhood, highlighted how dissociation can paradoxically protect the child through various disconnections within the self, both mentally and physically. Additionally, excessive activation of dissociative processes following interpersonal trauma in childhood can impair the cognitive and emotional processing of information, as well as the integration of mental, behavioural, and somatic states, including at the neurobiological level. This could increase the risk of emotional dysregulation and further traumatic experiences, leading to maladaptive developments. The researchers emphasised that these alterations in consciousness reflect an inability to integrate or combine information and experiences in a normal, predictable

manner. Consequently, thoughts and emotions become disconnected, bodily sensations fall outside conscious awareness, and repetitive behaviours occur without deliberate choice, planning, or self-awareness.

Dalton et al. (2019) emphasised on the importance of communicating with children on their parents' life-threatening conditions. This is because children are observant of their parents' condition, especially if they are constantly going to the hospitals and taking medications, which resulted in an obvious physical deterioration. Dalton et al. (2019) added that children tried to make sense of their parents' illness on their own and is often worse than the actual truth. As children' cognitive development often includes magical thinking, clear communication on their parents' condition could avoid misinterpretation, preparing them for the loss and enabling them to receive support. Meanwhile, it is reported in the study that adolescents who have a more develop cognitive level were very aware of their parents' condition and felt tension and anxious. The scarcity of information on the diagnosis lead to feelings of remorse and guilt regarding their potential part in causing or failing to prevent the death (Dalton et al., 2019).

Droser (2019) on parent-child relationships following spousal or parental death found that the surviving parents have difficulty providing support for their child or children. This stems from feelings of uncertainty about whether support is needed and that even if there is support, the child or children may not feel supported at all. This is because the surviving parent struggled with balancing her grief and keeping up with her children's grief and pain, as reported by another parent. Meanwhile, a participant who lost his parent reported that his mother shows support materialistically instead of the emotional support he and his siblings needed. Another participant also reported having uncertainty about supporting his grieving mother and letting her know that her children love her. These findings suggested that although the parents do not show care and love the way their children want but instead focus on what they think is necessary for them (e.g., the parent provides money but the children need his or her attention),

that does not mean they care any less. In spite of this, the kids could believe that they are not loved by their parents simply because the surviving parent loves them differently. As a result, their need for emotional support is ignored, which could lead to a rift in the parent-child bond (Droser, 2019).

Smigelsky et al. (2019) on investigating adolescents' attachment to the deceased and their relationship quality suggested that one of the risk factors for grief severity is the closer the parent-child relationship, the likelihood for grief severity increases. This is proved to be true as findings from the study stated that adolescents with anxiety and avoidance attachment suffer from grief more intensely. This is because they are highly dependent on their deceased parents and thus contribute to more distress once the parent is gone. Meanwhile, the inability of those with secure attachments to experience close relationships or have conflicts with their deceased parents leads to feelings of distress after the death. Hence, Smigelsky et al. (2019) believe that a conflicted parent-child relationship brings about unresolved issues between them and therefore causes anguish in adolescents.

2.6 Dealing with loss and grief

A study done by Sheffler et al. (2019) suggested two types of coping strategies which are problem-focused (PF) and avoidant emotion-focused (AEF). The study found that AEF contributed to the negative connection between ACEs and physical health problems. Specifically, individuals with a higher tendency to use AEF coping mechanisms reported more health problems growing up. Additionally, as expected, ACEs were associated with a lower tendency to use PF coping which is typically associated with better health outcomes. However, PF coping did not directly mediate the relationship between ACEs and physical health problems. These findings suggest that AEF coping is associated with poorer health and higher

mortality rates. The researchers elaborated that ACEs can heighten the sensitivity of brain regions involved in stress responses, self-control, and reward processing. These neurobiological and psychological changes can influence the way individuals perceive and respond to stressful situations. As a result, individuals with a history of ACEs are more likely to perceive situations as threatening and may adopt less effective coping strategies. This complex interplay of biological, psychological, and social factors contributes to an increased likelihood of experiencing stressors, heightened reactivity to stressors, and reduced coping effectiveness.

Boelen et al. (2021) studied the efficacy of Cognitive Behavioural Therapy (CBT) in dealing with prolonged grief in children and adolescents. CBT was found to be significantly more effective in improving symptoms of prolonged grief disorder (PGD) compared to other treatment approaches. CBT demonstrated its efficacy in alleviating PGD symptoms by promoting positive changes in negative thought patterns, reducing maladaptive coping mechanisms, increasing engagement in pleasurable activities, and enhancing social problem-solving skills. Moreover, CBT fosters emotional processing of the loss to facilitate healing. The study provided evidence that CBT interventions can effectively address symptoms of prolonged grief and increase resilience in facing challenges derived from bereavement.

A study by Larsen et al. (2021) suggested the eclectic use of techniques for group therapy dealing with grief and bereavement complications in adolescents. The eclectic techniques were made up of the dual process model of coping with bereavement, psychodynamic theory, and the narrative approach in which individual therapy is done simultaneously in a group therapy. This hybrid approach of individual therapy within a group setting aims to strike a balance between personalized care and peer support. By combining individual sessions with group therapy, clients receive tailored treatment for their specific needs while also benefiting from the camaraderie and shared experiences of others facing similar

challenges. This fosters a sense of community and reduces the isolation often associated with grief. The study resulted in clients not only gaining a deeper understanding and management of their grief but also embarking on a journey of personal growth. They gain newfound insights into themselves, their strengths, and their aspirations, leading to a heightened sense of self-awareness and self-empowerment. This transformation is attributed to their resilience, the expertise of their therapists, and the unwavering support of their peers, who provide a sense of normalcy and understanding.

Another effort made to study the professional interventions for grief and bereavement was a study done by Hill et al. (2019) through a pilot open trial of Multidimensional Grief Therapy. This study offers an initial assessment of the effectiveness of the intervention in addressing maladaptive grief reactions, depressive symptoms, and post-traumatic stress symptoms among bereaved youth. Participants who completed Phase I experienced significant reductions in all three domains of maladaptive grief, post-traumatic stress symptoms, and depressive symptoms from baseline, with large to very large effect sizes. Similarly, participants who completed Phase II showed significant reductions from the end of Phase I in two domains of maladaptive grief, as well as post-traumatic stress symptoms and depressive symptoms, with medium to large effect sizes. While acknowledging the need for further research with a broader range of outcome measures to comprehensively assess MGT, the present study provides initial evidence supporting the effectiveness of MGT as a treatment approach for bereaved and grieving adolescents.

2.7 Positive Psychology as a Coping Strategy

Andriessen et al. (2018) propose that death may have a beneficial effect on an individual's personal development. According to one study participant, death made her appreciate life and her relationships even more. Additionally, it provided more maturity in which the death gave rise to new life aspirations—adolescent began to exhibit more autonomy

in determining their priorities and objectives as a way to continue living life and moving on from the death. Additionally, participants reported feeling more empathic toward others who experience similar losses. Therefore, it is seen here that death had provided the adolescents with life lessons on how it changed their perspective on life and self-care which is related to the confrontation with the death.

Grief and positive psychology may seem like two opposing concepts, but they actually have a complex and intertwined relationship. While grief can be a debilitating experience, it is also a normal and healthy part of the human experience. Positive psychology can help individuals cope with grief and promote well-being in several ways. To support this, a study by Laakso (2023) found that the use of positive psychology as a coping strategy could aid in decreasing loneliness in adolescents. According to Seligman's theoretical framework for happiness, a fulfilling and flourishing life hinges on comprehending the 'five core elements of psychological well-being and happiness (Seligman, 2002 as cited by Nicholson, 2018). The name PERMA model is a made-up acronym using initial letters of each domain which are Positive Emotions, Engagement, Relationships, Meaning, and Accomplishment. Seligman (2002) proposed that happiness is defined as a state of internal equilibrium achieved through self-awareness, resilience, self-acceptance, and nurturing relationships. These domains work synergistically to cultivate happiness (Sonker et al. 2022).

i. P – Positive Emotions

The common adage of the glass being half full or half empty reflects an individual's tendency towards optimism or pessimism. While pessimism can play a role in survival strategies and preparing for negative scenarios, optimists are generally more likely to experience a fulfilling life. By adopting an optimistic perspective and reframing negative thoughts into opportunities for further happiness, individuals

can cultivate a positive outlook toward the future (Nicholson, 2018). In this study, adolescents try to think positively about the death, that their parent's death indicate that they do not have to suffer from the illness anymore.

ii. E – Engagement

Engagement relates to feelings of attachment, participation, attention, and level of interest in leisure, hobbies, or employment. The state of flow, in which time seems to stand still, one loses all feeling of self, and focuses intently on the present, is a crucial idea (Seligman, 2002 as cited in Sonker et al. 2022). When one starts to fully engage with the present moment and concentrate on doing the activities then experience the state of being known as "flow" (Seligman, 2002). In other words, our bodies are actively inundated with endorphins and hormones that improve our mood and produce a "flow" of immersion that engrosses us in the action. The question that arises here is how one can achieve the state of flow even in challenging circumstances (Seligman, 2002 as cited in Nicholson, 2018). In this study, engagement relates to how adolescents try to live life after the death. They engage in more positive social relationship and activities. This includes spending more time with family and friends and indulge in hobbies. Adolescents who grow up in low- and middle-income family may push themselves academically to provide better living for their families in the future.

iii. R – Relationships

The ability to foster meaningful relationships and maintain strong social bonds is an essential aspect of human existence (Seligman, 2002 as cited in Sonker et al. 2022). Individuals thrive on durable social connections, which provide

opportunities for love, intimacy, and personal growth. Nurturing and strengthening positive relationships has been shown to significantly enhance overall life satisfaction (Seligman, 2002 as cited in Nicholson, 2018). Death provides realisation that loss is inevitable. Hence, it allows the adolescents to appreciate relationships better.

iv. M – Meaning

Seeking meaning in life is a fundamental human aspiration, driving our sense of purpose and fulfillment. Unlike materialistic pursuits, finding meaning is not about acquiring possessions but rather about discovering the reason for our existence. It compels us to connect with ourselves and others, fostering a sense of belonging and shared purpose (Seligman, 2002 as cited in Nicholson, 2018). Grief is a strong emotion. Feeling such strong emotion requires complex integration. Hence, adolescents who find the meaning of the grief are able to understand it better. As a result, they can find better ways to cope and not dwell on their emotions to the point that it affects them negatively.

v. A – Accomplishment

A sense of accomplishment stems from setting and achieving personal goals. The dedication and effort required to reach our objectives brings immense satisfaction. By setting attainable yet challenging goals, we cultivate a sense of accomplishment that fuels our growth and contributes to our overall well-being alongside the other components of PERMA (Seligman, 2002 as cited in Nicholson, 2018). In this study, accomplishment would mean the adolescents have move on from the death. Letting go and accepting the loss with an open heart, as well as continuing their life and

grow positively from the impact with an appreciation on life is an accomplishment that could increase their quality of life.

According to the 5 stages of grief as proposed by Elisabeth Kübler-Ross (1969), grieving adolescents go through denial (adolescents simply cannot accept the death), anger (adolescents are mad at the illnesses for taking the life of their beloved ones), bargaining (adolescents go through a desperate but useless attempt for salvation by promises to change behaviour or undo past wrongs. Guilt become a significant emotion in this phase in which adolescents blame themselves for not being able to prevent the death), depression (adolescents feel helpless as they start to accept the reality that their loved one is not coming back), and acceptance (adolescents learn to let go and live life without their loved one. Adolescents also start to invest in family relationships and friends.) However, it should be noted that the adolescents do not necessarily follow the 5 stages in the stated order, and some may go through multiple stages simultaneously (Kübler-Ross, 1974).

While religion may assist in coping with grief, a traumatic experience like parental death often results in adolescents questioning God about their misfortune (Mosher, 2018). This is because adolescents' capability for existential and abstract thinking leads them to challenge their existing religious beliefs and familial worldviews. Mosher (2018) also added that despite the doubt in their religion, adolescents who initially went through life without faith in God or any other beliefs started to explore spirituality.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter describes the methods that were used in the research in order to achieve the set objectives of this research. It contains the research design, research population and sample, pilot study, research instrument, data collection, and data analysis.

3.1 Research Design

This study used qualitative research methods that support the approach of social constructivism. This approach to social constructivism is often combined with interpretivism. An individual creates subjective meaning to their experiences through the things they go through, and it is interpreted based on historical and social perspectives as expressed in social constructivism (Creswell & Creswell, 2018). This research aims to explore the psychological well-being of grieving adolescents in UNIMAS, so the researcher seeks to understand the participants' experiences. Hence, it is best that the information gained is interpreted personally and in detail by the participants themselves (Creswell & Creswell, 2018). The interpretation of the data is entirely from the data collected, not based on the researcher's interpretation because a qualitative study is highly inductive (Creswell & Creswell, 2018).

Other than that, the qualitative method is appropriate because it allows researchers and participants to express their experiences and feelings using their own words without any hesitation. This is due to the qualitative design that is flexible and

smooth, which encourages free and clear exposure (Muzari et al., 2022). Creswell & Creswell (2018) also mentioned that the interview questions should be open as this allows the participants to give meaning to their life stories in their own words. Moreover, qualitative research also allows researchers to learn how a person gives meaning and learn about his life, and understand themselves and others (Hamilton & Finley, 2019; Muzari et al., 2022). Hence, the qualitative methods enable the researcher to capture the subjective experiences of grieving adolescents.

3.2 Research participants

The participants are university students aged from 19 to approximately 25 years old, which fits the criteria, and the researcher was able to observe the experience of grief undergone by the participants during their adolescence and how it impacted their growth through their early adulthood.

The sampling method of this study was purposive sampling. The purposive sampling method was a non-probability sample where only participants from the inclusion criteria were recruited. The intended sampling method aims to ensure that the sample is relevant to the research questions posed by recruiting participants strategically.

The inclusion criteria of this research are the participants who were:

- UNIMAS students
- Experience parental death during adolescence (10-20 years old)
- Male or female participants

The exclusion criteria for this research are the participants who were:

- Not a student from UNIMAS

- Does not experience parental death during adolescence (10-20 years old)
- Participants who refused to give informed consent to the researcher

The researcher needed to ensure that the selected participants were best helped in understanding the research problem and the research question to the point that no new information or themes are observed in the data or the concept of saturation (Creswell & Creswell, 2018). Therefore, the researcher chose 8 participants.

3.3 Pilot study

A pilot study was done to ensure that the interview questions were suitable and reliable before the main study was conducted. According to Williams-McBean (2019), a qualitative pilot study assists in evaluating the practicality of the research methods and procedures. It helps to identify any potential problems with the data collection, recruitment, analysis, or other aspects of the research design. Williams-McBean (2019) added that a pilot study not only provides the required details for the estimation of the sample size but also for the evaluation of all other aspects of the main study, reducing researchers' and participants' unnecessary initiatives, as well as the dissipation of research resources.

Therefore, to perform a pilot study, the researcher has chosen 1 participant to participate in the study since the participant would be 8 people, and answer questions during the interview. Once the data were collected, the data were analysed in terms of the participant's capability of understanding the questions. It was also analysed by interpreting how detailed the answers were from the participants and whether those answers helped achieve the researcher's objectives. Hence, the researcher was able to know which sections need improvements and changes.

In the pilot study that has been done, the researcher found that the majority of the questions were understandable by the participants and could help achieve the study's objectives.

3.4 Data collection

The primary source of information for this research was the experience of grieving adolescents. In collecting data, a semi-structured interview approach was used. This is because a semi-structured interview allows for flexibility in the elaboration of information given by the participants and follow-up questions by the researcher (Alshenqeeti, 2014). Hence, the researcher can discover participants' thoughts, perceptions, feelings, and experiences expressed through their own words (Alshenqeeti, 2014). The researcher approached the participants through personal connections.

An interview guide was also provided. It was used as a guide in conducting the semi-structured interview. The interview guide assisted in providing the researcher with predetermined questions, while also containing open-ended questions that allow participants to express their experience relevant to the objectives to achieve an in-depth understanding of the study (Ruslin et al., 2022). The interview lasted between one to two hours per session. All interview sessions were recorded for transcription purposes and will be deleted after the research is done.

3.5 Data analysis

The audios of the interviews were stored online in *Google Drive* to avoid loss of recordings from broken physical storage and were transcribed. After the process, the audios were listened to again to make sure the transcripts were the same as the

recordings. As a matter of confidentiality, the recordings and transcript will be deleted after this research is done.

The researcher chose thematic analysis as the data analysis approach. This is because the approach is a flexible research tool for providing rich and detailed data (Braun & Clarke, 2006). Thematic analysis also helps in analysing various types of data; big or small sets of data and various research questions as well as producing data-based or theory-based analysis (Braun & Clarke, 2006). The study emerges from the data collected by the researcher rather than applied by the researcher making thematic analysis an inductive method (Norris, 2017). Based on Braun and Clarke (2006), thematic analysis is defined as an analytical approach that concerns identifying, interpreting, and documenting data trends known as themes. It is suggested that thematic analysis should be the first qualitative method that a researcher needs to learn as it can be used in many other types of analysis (Braun & Clarke, 2006).

There are various approaches to conducting thematic analysis, but the most common form follows a six-step process:

Familiarisation	This first step required the researcher to familiarise themselves with the data collected by transcribing data, reading, and re-reading the data, and noting down the main ideas.
Coding	Interesting features of data were coded which includes the entire data set and collecting each data relevant to each code that has been generated.
Generating themes	This step combined the code into a potential theme as well as collected data related to each potential theme.

Reviewing themes	The themes were reviewed to ensure they were compatible with the code that had been generated and the entire data set.
Defining and naming themes	Ongoing analysis was done to refine each existing theme as well as generate clear definitions and names for each theme.
Writing up	This step is the last opportunity for the researcher to analyse. Then, interesting examples were selected while analyses were associated with research questions and literature. Finally, specific reports based on analysis were produced.

Table 1: Braun & Clarke Thematic Analysis

CHAPTER FOUR

FINDINGS

4.0 Introduction

This chapter includes demographic information of the participants and findings from the semi-structured interviews of this study. The participants' names are not their real names and do not reflect their true identity.

4.1 Demographic information

Participants	Age	Age when parent deceased	Ethnicity	Place of Origin	Deceased parent	Number of siblings (Order of siblings)	Family's economic status
Ann	22	12	Bidayuh	Bau	Father	4 (1)	B40
Chee	24	17	Chinese	Kuching	Father	2 (1)	B40
Aisyah	22	18	Malay	Miri	Father	7 (7)	M40
Kenneth	22	18	Iban-Kenyah	Bintulu	Mother	3 (2)	B40

Siti	21	13	Malay	Bangi	Mother	3 (3)	M40
Regina	22	18	Bidayuh	Serian	Mother	2 (2)	B40
Justin	22	17	Iban	Kuching	Father	3 (2)	B40
Natalia	22	15	Iban	Bintulu	Father	3 (3)	B40

Table 2: Participants Demographic Information

For this study, the researcher interviewed 8 participants from UNIMAS, consisting of 5 females and 3 males. 7 of the participants are from Sarawak and only 1 participant is from West Malaysia, specifically Bangi, Selangor. All the participants are currently in UNIMAS for their studies and have lost a parent in their adolescence.

4.2 Findings

This study was conducted qualitatively through in-depth interviews with the participants. Semi-structured questions were used to help the researcher achieve the research objectives. There are 3 main themes and 10 subthemes that emerged through the data analysis. The participants shared their experiences in dealing with grief during and after their parents' death focusing on the risk factors of grief after losing their parents, the challenges they faced and how they were affected by the death, as well as the coping strategies that they adopted:

Themes	Subthemes	Category
Theme 1: <i>We Don't Talk About Him</i> Risk factors of grief in adolescents after parental death due to long-term illness	Grief communication	Lack of expression of grief
	Family dynamic	- The relationship between the deceased parent and the adolescent - The relationship among the family members after the death

	Age	• Vulnerability
Theme 2: <i>I Felt Helpless</i> Challenges and effects of parental death on adolescents' well-being and throughout their adulthood	Emotional struggle	• Intense sadness • Guilt • Resentment towards family members
	Physical struggle	• Taking care of the sick parent before the death • Change of appetite • Change of behaviour
	Financial struggle	• Financially aware at a young age
	Positive aspects	• Becoming more appreciative • Stronger bond with family • Increased motivation
Theme 3: <i>And I'm Letting Go</i> Coping strategies for grief in adolescents after parental death due to long-term illness	PERMA Model of Well-being	• Positive Emotions • Engagement • Relationships • Meaning • Accomplishment
	Kübler-Ross 5 stages of grief	• Denial • Anger

		• Bargaining • Depression • Acceptance
	Religion	• Expression of grief

Table 3: Themes, Subthemes, and Category based on findings

4.2.1 Theme 1: *We Don't Talk About Him*

Risk factors of grief in adolescents after parental death due to long-term illness

The participants were exposed to some risk factors that could aggravate their grief after parental death due to long-term illness.

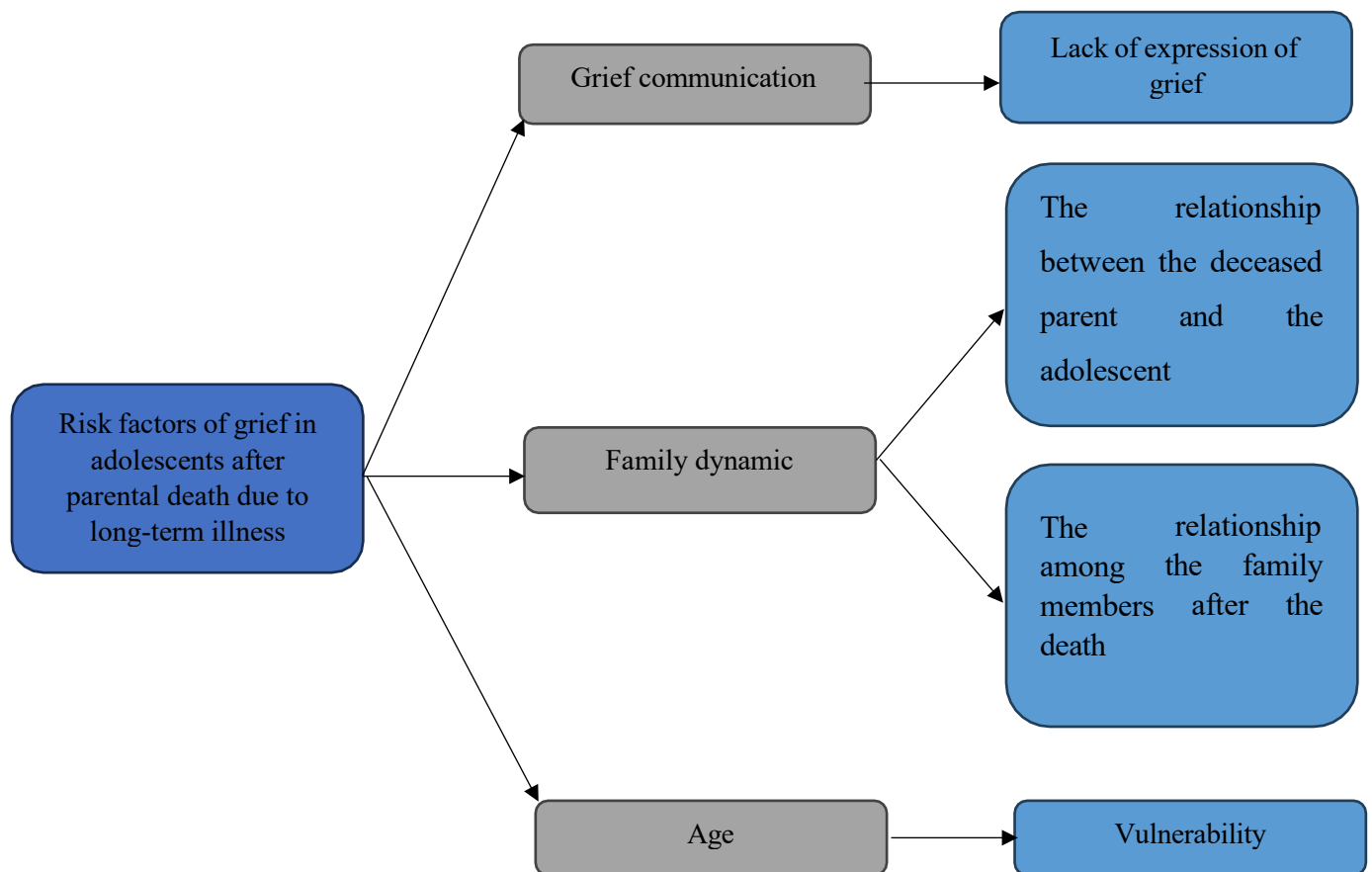


Figure 2: Theme 1

4.2.1.1 Grief Communication

Lack of expression of grief

Analysis of data revealed that one of the risk factors is the lack of expression of grief from the adolescents and their family members. The expression of grief being discussed is mainly about talking about the death. As mentioned by Regina and Natalia, the lack of grief expression was because they refused to remember the pain. Besides, they were also trying to protect their family members' feelings to not trigger the traumatic experiences. As a result, they often go around avoiding their real feelings and ensuring everyone they were okay after the death even though they were not.

Bila I avoid, I avoid everything and my family pun macam sik kelaka gilak la pasal nya. (Aisyah).

(When I avoid, I avoid everything and my family really don't talk about him too).

No, no, honestly. When people ask me if I'm okay, I just said 'I'm okay' (Kenneth).

No. I don't really talked about it (the grief) because I think my sister dah banyak beban, sekarang dia perlu kerja untuk tanggung kami berdua, jadi saya rasa tak perlu la saya nak tambah beban dia untuk fikir pasal saya (Regina).

(No. I don't really talked about it (the grief) because I think my sister already has a lot on her shoulder. Since she have to work to take care of both of us, I feel like I should not add more weight by making her think about me).

We don't really talk about him (the deceased father) because what happened to my father was very traumatic and very sudden, the accident, the death... no one really see it coming. So, I don't have time to process everything and suddenly my life kind of turned upside down. My entire routine, my father, my family, my life, they all change altogether so it was very very hard for me. When I remember him, I also remember all the hard time we have to go through (Natalia).

4.2.1.2 Family Dynamic

The relationship between the deceased parent and the adolescent

From the interviews, it was found that the relationship between the deceased parent and the adolescent held a significant role in determining the intensity and the timing of grief in the adolescent. In this part, the focus is on the negative side of the family relationship. Participants who were not close with their deceased parents or had an absent parent-child relationship were reported to grieve less intensely as time went by.

My father and my mother actually divorced when I was in secondary school (Kenneth). When asked if the participant is close with his mother, he answered, 'Not really, biasa-biasa jak.' This further explains his answer to whether he is still grieving for his mother, 'I do, but not too much anymore.' (Kenneth).

'Sebab kami tak rapat sangat, actually.' ('We're not really close.') When asked if the participant felt abandoned by her own mother, she answered, 'Hmm, ada juga la. Sebab, saya anak dia juga kan. So, bila dia tak bagitau, saya pun taktau. Tapi, bila dia sakit, dia bising, dia marah-marah and selalunya saya yang kena tempias. Jadi, for me, kalau dia bagitau saya yang dia sakit, mungkin saya at least dapat tolong dia.' (Regina).

(Yes, the feeling of being abandoned is there because I'm her daughter too. So, when she did not tell me, of course I did not know as well. But, when she's in pain, she gets mad and I am always the one who have to suffer from her anger. Hence, for me, if she had told me that she's in pain, maybe I could have at least help her).

When asked if the participant is still grieving for her mother, she answered, 'Ya, a bit. Kadang-kadang kalau duduk sorang-sorang dalam bilik tu terfikir jugala, apala nasib saya macam ni... macam tu. Kalau nangis tu, masa awal-awal dulu ada juga, tapi sekarang dah jarang.' (Regina).

(Yes, a little bit. Sometimes when I sit alone in my room I wondered, why is my life like this? I cried during the early stage but it rarely happens now).

The relationship among the family members after the death

From the interview, the absence of a nurturing family relationship and deterioration of the relationship among family members after the death could be one of the risk factors for the

intensity and timing of the grief. Kenneth and Justin explained that their family members did not care about their emotions after the death. As a result, they were unable to share their grief with their family members and left to deal with it on their own. Kenneth particularly explained how instead of attending to him emotionally, his father only managed to provide him material-wise.

Maybe, during my mother just passed away, awal-awal, he got like, he cares more about us during that time, which is logic la because ya la, she just passed away kan. But, eventually, his attention to us macam biasa jak, he doesn't really call or text us, sometimes he would bank in money for us, my yuran for asasi also, he was the one who pay it (Kenneth).

I feel like I've become more distant with my family... emotion-wise. Because I feel like since I already express a lot of my feelings, my disappointment to them when I was still taking care of my father, there isn't a lot of things I wanted to say anymore. It's kind of ended there. And, they never really asked how I felt, if I'm tired, if I'm angry... all they know is that I have to take care of him, because they have other 'responsibility', as if I don't (Justin).

4.2.1.3 Age

Vulnerability

Age has become a risk factor for adolescents as they are vulnerable to changes and how it affects the change in their behaviour and values later in their lives. Ann went through anticipatory grief for her father. Kenneth and Justin expressed their inability to have freedom because they were taking care of their parent while Natalia was unaware of what grief was when his father passed away.

Actually... the grief hits me later. Not directly during the death. But also I think masa saya jaga dia tu, saya dah tau yang dia tidak lama lagi dengan kami, so masa tu saya dah grieving, berduka... so masa dia meninggal, saya tak rasa apa-apa. Saya just focus jaga rumah, jaga adik-adik, ya la kan sebab perlu ada orang atur makan minum untuk orang yang datang kan,

saya pula anak sulung. Jadi, masa dia meninggal, jenazah dia di rumah, saya tak rasa apa-apa. After that, after my mum dah mula bekerja, saya rasa dibiarkan untuk buat tanggungjawab rumah sendiri, di situ yang saya rasa 'kenapa lah benda ni terjadi kepada saya?' (Ann).

(Actually, the grief hits me later. Not directly during the death. But, I also think that I started grieving for him when I was taking care of him, knowing that it won't be long before he left us. Hence, I felt nothing when he passed away. I just focus on taking care of the house, and my siblings, as there have to be people who serve the guests who come to visit, not to add I am the oldest child. So, when his corpse was at the house, I felt nothing. After my mum started working, I felt like I was left all alone with the house responsibility, and at that time I questioned 'Why must this (the death) happen to me?')

I would say it is less stressful? Not in a way that I'm grateful that she passed away, no. More like less stressful in a way that I am finally able to think about myself... umm, do you get me? Because after she passed away, I felt relief that she doesn't have to suffer anymore, I don't have to suffer anymore. Before this, I feel like macam telur di hujung tanduk macam tu, macam saya menunggu masa untuk dia pergi so that makes me nervous...stress la macam tu (Before this, I feel like I'm on the edge, like I'm just waiting for her to leave so that makes me feel nervous and stressed out) (Kenneth).

Masa saya tau tu, saya rasa otak saya jadi blank, saya just fikir nak balik, nak jumpa dia (Regina).

(When I knew that she had passed away, my mind went blank. I just thought of going back and see her).

Thinking back it scares me how much I wanted him off my life back then because he was a burden to me. I cannot enjoy my life like other kids, I cannot have my father come to school, even my mother too don't really come to school (Justin).

I know it is normal to feel sad but I didn't expect it to be that way and that long... because I didn't know about the concept of grief back then, I was still a kid, so it's a very new experience (Natalia).

4.2.2 Theme 2: *I Felt Helpless*

Challenges and effects of parental death on adolescents' well-being and throughout their adulthood

This theme covers the challenges and effects of parental death on the emotional, physical, and financial struggles of the adolescents. The struggles cover from the moment of the parent's diagnosis, taking care of them and after the death. This theme also includes the positive aspects of the parental death.

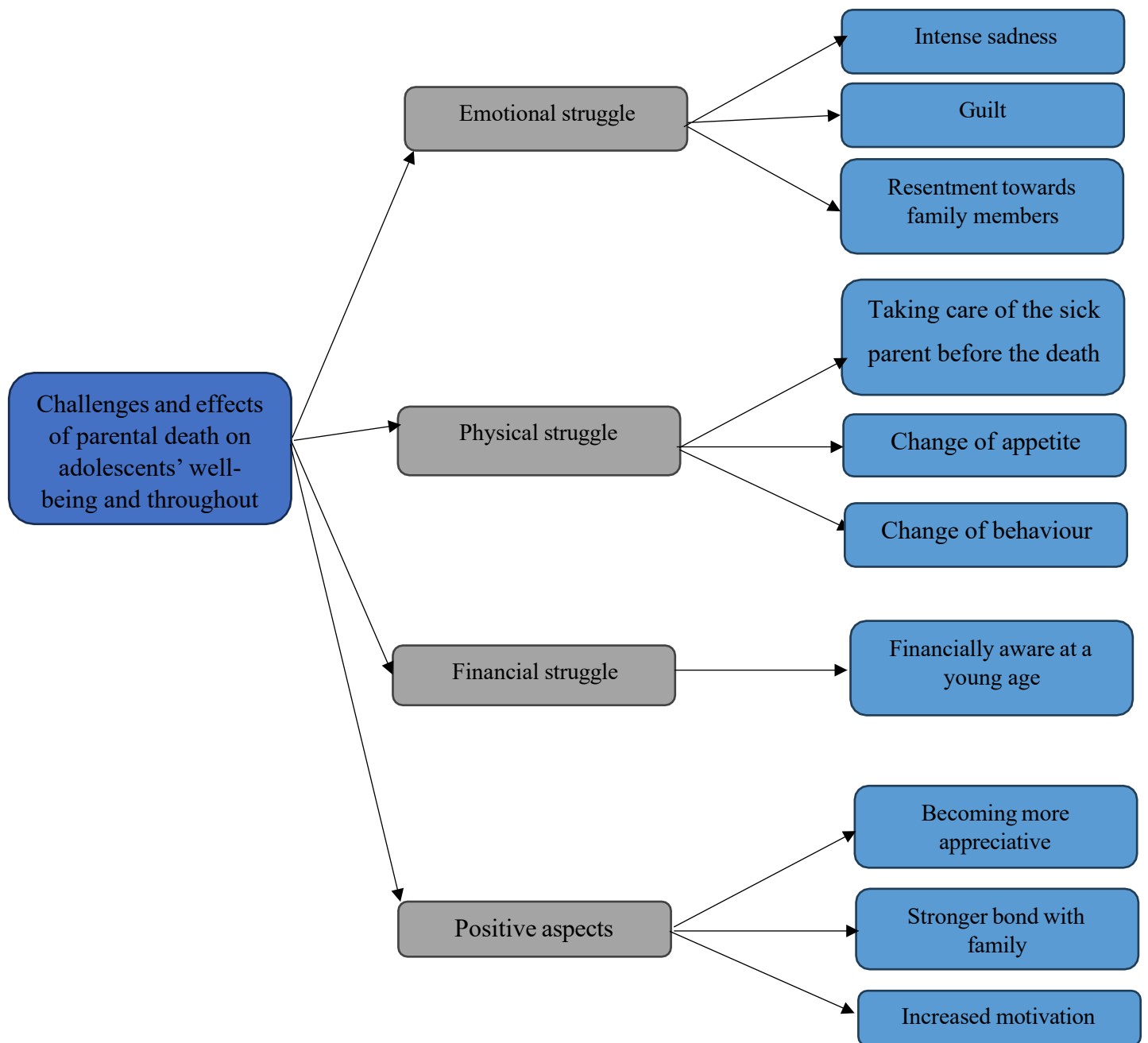


Figure 3: Theme 2

4.2.2.1 Emotional Struggle

Intense sadness

From the interviews, sadness is a prominent feeling felt by the participants after going through parental death. Despite that, the participants reported that they tried to conceal their sadness and kept it to themselves. Chee and Siti expressed that they were unable to hide their emotion and Siti resorted to self-isolation. Meanwhile, Aisyah reported that keeping her sadness to herself was a defensive way to the point that it became uncomfortable to talk about her experience. On the other hand, Kenneth went through anticipatory grief and his intense sadness made him question his situation.

I try to hide it, console my mother and my brother but I ended up crying like them too (Chee).

When I'm alone in my room, suddenly the feeling just come out of nowhere and then I cry (Chee).

Memang pendam sendiri (the sadness)... Nya punya consequences I think bila nya macam kita mok discuss pasal kita pun experience, nya akan jadi uncomfortable. Nya macam 'eh better aku pendam sendiri jak, orang lain sik kisah pun' (Aisyah).

(I keep the sadness to myself. Eventually, when I want to discuss on my experience, it become uncomfortable. It's like, 'it's better if I just keep it to myself, no one cares anyway).

I think for most of the time, I feel suffocated? Tired? Like when is this going to end? (Kenneth, while taking care of his mother)

After my mum passed away, seminggu I tak keluar bilik, I kunci pintu, I nangis apa semua, sumpah memang teruk I nangis masa tu, my dad sampai perlu pecahkan pintu bilik (Siti).

(After my mum passed away, I did not go out of my room for a week. I locked the door and cried so badly until my dad had to break the door).

Guilt

The results of the interviews showcased the feeling of guilt by the participants to their deceased parents and other people. The guilt stems from hurting the existing relationship due to negative thoughts and emotions. Ann expressed her guilt in her romantic relationship, which was ruined by her unregulated emotions. Kenneth described his guilt about his unamended relationship with his mother while Justin felt guilty for feeling relieved after his father passed away.

My boyfriend pun... mungkin saya masih dengan dia sekarang kalau semua benda ni tak berlaku dulu. There's a lot of guilt and regret, semua benda yang saya tidak dapat buat, semua orang yang saya sakiti, I feel like if my father passed away now, I would have understand how to regulate my emotions better, so there won't be as much loss (Ann).

(I could have still be with my boyfriend now if all of this does not happen. There's a lot of guilt and regret, all the things I could not do and all the people I've hurted. I feel like if my father passed away now, I would have understand how to regulate my emotions better, so there won't be as much loss).

She's still a bit cold, but she still talk to me, like having a conversation but I didn't layan her that much, ya la... I macam a bit menyesal juga la on that part because I didn't try to fix our relationship... pikir diri sendiri jak (Kenneth).

(She's still a bit cold towards me, but she still talks to me but I didn't entertain her that much. I feel regretful on that because I didn't try to fix our relationship. I only think about myself).

I feel all sorts of thing when he was alive but when he's gone I don't feel anything. I was relief, yes, but I feel guilty for feeling that way because as if I was waiting for him to pass away (Justin).

Resentment towards the deceased parent or family members

It was also found from the interviews that the participants could not help but feel resentment towards their deceased parent or family members for contributing to the severity of the illness which eventually caused the death. Ann described her resentment towards her parents while Justin expressed it to his family members who did not care enough for themselves and the sick parent.

Sometimes I'm mad at my father for smoking and drinking too much, I'm mad at my mother for not stopping him. Now I have to be the one yang take responsibility for my family and my mother have the audacity untuk tidak kisah dengan my effort for this family? So I studied hard so I can get out of that house (Ann).

I felt very angry. I was against everything. I hate my mother as well because she kept on telling me to take care of my father. And taking care of my father requires a lot of mental and physical effort because when he throws tantrum, I have to hold him down or else he would smash things. That for me was very draining (Justin).

4.2.2.2 Physical Struggle

Taking care of the sick parent before the death

This subtheme explains the struggle the participants go through while taking care of their sick parent before the death. The participants struggled with seeing their sick parents change physically and how their attitude and behaviour changed from the person they used to know. Natalia explained that she went through physical exhaustion from taking care of his sick father and was unable to enjoy her own time.

Helpless... to see the person who has always taken care of us being taken care of, and to see that his body was very weak... I felt... like my world is falling apart, to see a person this strong can suddenly be so weak. Especially after seeing him becoming so thin and he is already thin for me (Chee).

Yang paling difficult is bila nak bagi makan, sometimes dia muntahkan balik makanan tu, macam tekak dia tak boleh terima. So macam 'tak boleh macam ni, mama kena makan' sebab logic akal masa tu, kena makan supaya cepat sembuh kan walaupun sebenarnya dia tak nak makan sebab condition dah makin teruk. So, bila benda tu jadi, I rasa nak nangis sangat-sangat, I cakap 'mama makanla sikit', I cakap sekali I nangis, I suap dia, macam I harap sangat, I beg for her untuk makan (Siti).

(The most difficult part is when I'm feeding her, she sometimes vomits the food out. My logic at that time was that she has to eat so she can get better although actually she refused to eat because her condition is getting worse. When that happened, I felt like crying. I told her to just eat a little bit and I feed her, I was begging for her to eat).

Since my sisters are the one yang usually buat house chores so, most of the time my mum depend on me to take care of my father. So, I don't really do anything else except for taking care of my

father and sometimes that makes me really tired because they can take a break from it by saying that they have to do something else but I cannot (Natalia).

Change of appetite

According to the interviews, it was found that some participants struggled with a change in appetite after the death. The change went towards two extremes in which Siti explained she could not eat at all while Natalia battled with body image issue as she was binge-eating.

I memang takda selera nak makan, seminggu tu jugala I tak datang sekolah (Siti).
(I have no appetite at all and I did not come to school for a week).

But I remember not feeling anything and I eat a lot, like a lot... And when I start to feel sad, I don't eat, I don't do anything at all. I think that happened for like 2 to 3 months after my father passed away. Because of that I actually struggled with my weight also. Since I eat a lot and eat while binge-watching, my weight increase a lot so I struggled with it and how my body looks, how it suddenly change. I remember feeling very low self-confidence and I wear mostly oversized clothes to hide my body (Natalia).

Change of behaviour

The participants also reported noticing changes in their behaviour starting from before the death— during the phase of early diagnosis and care until after the death. Regina and Natalia described how they changed into a more quiet person while Ann became hot-tempered. Siti stated that the death of her mother caused turmoil to the point that she felt lost and became clueless in life.

I think right after my father passed away saya jadi hot-tempered. Saya cepat marah dekat semua benda, semua orang (Ann).

(I think right after my father passed away, I became hot-tempered. I get angry easily at everything and everyone).

I become clueless and macam takda arah kehidupan (Siti).

(I become clueless and as if I have become lost in life).

I become more quiet, more reserved, I don't really talk a lot after that, and I don't go out of my room, don't really join any activities di campus, memang saya menyendiri (Regina).

(I become more quiet, more reserved, I don't really talk a lot after that, and I don't go out of my room or join any activities in campus. I isolate myself).

I started to talk less and follow everything everyone says, especially what my family says. Although I only take care my father for a year but I feel like I have been doing that for a longer time, it feels like a routine for me (Natalia).

4.2.2.3 Financial Struggle

Financially aware at a young age

This subtheme explains the financial struggle the participants have to go through which caused them to be financially aware at a young age. The results from the in-depth interviews revealed that most of the participants struggled financially and had to witness their family members deal with financial constraints. Some of the participants explained that they felt pity of their family members for having to do extra work to provide for the family. The pity led them to think of wanting to complete their studies fast. On the contrary, Regina had thought of quitting her studies to help her sister. Justin specifically described his incapability to enjoy his teenage life hanging out with his friends because of his limited spending.

Sometimes, I would go home during weekends... long cuti, like 3 days cuti. My mother open this food stall at the food court during weekend so I go help her there during weekends... That's

why I want to finish my studies faster, get a job, so that she (his mother) don't have to do like extra work (Chee).

Financially... struggle juga la, since my sister is the only one that can provide for us. I try to work after my mother passed away but I terus dapat tawaran untuk sambung asasi di UNIMAS. The struggle was after that la, bayar yuran and everything, now pun still struggle but I got a scholarship to cover my yuran for me (Kenneth).

... kesian dengan kakak saya sebab dia perlu hadap semua benda sendiri, sampai saya terfikir juga nak stop study untuk tolong dia (Regina).

(I pity my sister because she has to face everything alone, and that makes me think of quitting my study).

I think financially, personally for me I was struggling even though my mother and sister is working. But, since our relationship is not really good with each other, I don't really asked money from them. I only wait for them to give money to me themselves. So, I had to really limit my spendings so that it is enough for one month, because they give me money every month. Sometimes, if my friends ajak me to go out, lepak, I cannot go because yea... you have to pay yourself kan (Justin).

The insurance covered the hospital fees and everything but eventually we... ada rasa susah sikit la because my mother is not working and all of us are still studying as well. But after my father passed away, my mother started working again and we also got pension from my father so until now, we're okay, boleh survive lagi (Natalia).

4.2.2.4 Positive Aspects

Becoming more appreciative

From the interviews, the participants found themselves to become more appreciative of their lives and the people in them. The participants commented on how their parents' death restructured their values in lives and that their family members became their priority. Chee recognised that he does not need to forget the death although it was painful, but used it as a reminder that he will go through a lot more loss in his life.

Remembering his pain lets me to appreciate life better, seeing the reality... that people don't live forever and I would have to witness a lot more loss in the future, and deal with it, move on, letting go (Chee).

Try to appreciate my life, appreciate orang-orang yang masih ada (Aisyah).

(Try to appreciate my life and appreciate those who are still around).

Now I'm letting go everything, and just try to appreciate the people that stays, like my siblings (Kenneth).

I did not take things for granted macam dulu, and I become lebih appreciate apa yang ada dalam hidup I sekarang, especially my family and friends (Siti).

(I did not take things for granted like before and I become more appreciative with what I have in my life right now, especially my family and friends).

That's how my life is right now, I won't say that I'm happy, I'm not sad either but maybe just trying to appreciate everything (Justin).

Stronger bond with family

Feeling more appreciative led to a stronger bond with family. The interviews discussed the change in the family relationship and how some participants noticed the stronger bond within the family. Aisyah, who was not close to her mother and how she described her as cold and less attentive of her, became closer to her mother after her father passed away. Meanwhile, Kenneth found comfort in enjoying his sister's presence after his mother's death. It was also found that the family bond is stronger for participants who live far from their immediate family in which social support is limited. Therefore, they tend to grow closer to those present in their daily lives which are their surviving parents and their siblings.

We are still close with each other, even closer I think. Since it's just the three of us left now (Chee).

Tapi after my dad passed away, nya (her mother) everyday text me, tanya apa khabar, apa polah hari tok, makan apa, so jadi sangat rapat lah (Aisyah).

(After my father passed away, she text me everyday, asking how I'm doing, what am I doing, what I eat, so we became closer).

Because now, since I always eat with my sister, I realised the comfort it brings to just sit and eat together (Kenneth).

We got closer, especially me and my dad (Siti).

Increased motivation

Following the death of their parents, participants mostly obtained increased motivation to finish their studies. One of the reasons for this is to help provide for their family, especially for their surviving parents. Besides, the participants are motivated because they are inspired by their deceased parent's occupation and are able to do things they could not manage to do while their parents are still alive. Specifically, Aisyah mentioned how she wanted to study medicine and get a job in the medical field just like her father so she could help people around her.

I would say I become more motivated to finish my study (Chee).

Ada motivation untuk belajar, jadi motivated untuk jadi macam my father dolok... So motivation ya memang adala especially sebab my mother dah sorang nak, mok belajar so that boleh happy kan nya... belajar bagus-bagus, dapat kerja bagus-bagus (Aisyah).

(I am motivated to study and be just like my father. There is the motivation especially because I only have my mother now, I want to do my best in my study and get a good job to make her happy).

Motivated untuk habiskan degree dengan cemerlang, dapatkan kerja, sebab I nak travel. One thing in my bucket list is travelling, and it's also one of the things yang I tak sempat nak buat dengan my mum (Siti).

(I become motivated to finish my degree with flying colours, get a job because I want to travel. One thing in my bucket list is travelling, and it's also one of the things yang I tak sempat nak buat dengan my mum).

4.2.3 Theme 3: *And I'm Letting Go*

Coping strategies for grief in adolescents after parental death due to long-term illness

This theme discusses the coping strategies adopted by adolescents during their grieving period.

This theme will also highlight how the theories are used to understand grief experiences and how each aspect of the theories is utilised as a coping strategy.

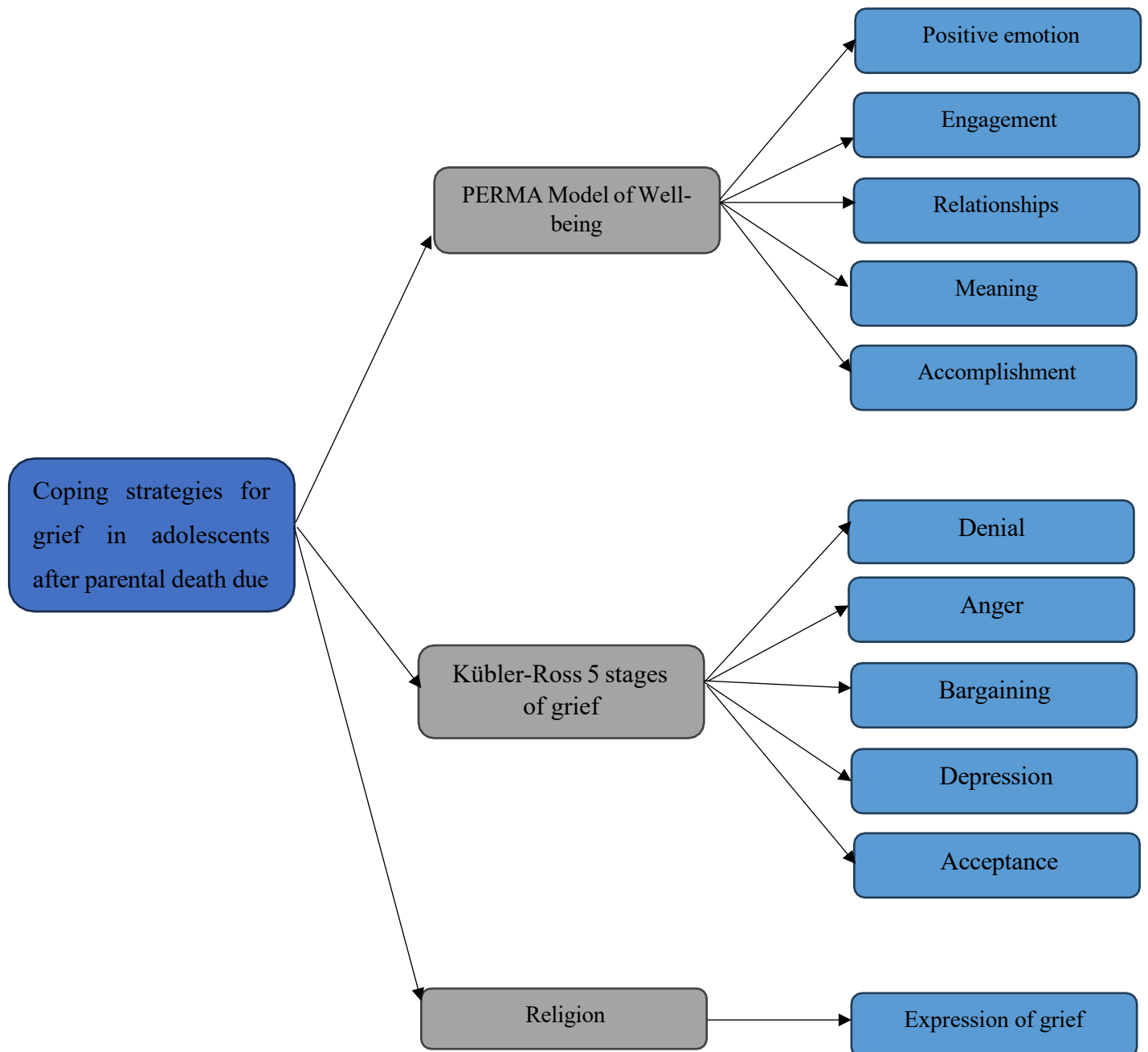


Figure 4: Theme 3

4.2.3.1 PERMA Model of Well-being

In this subtheme, the PERMA Model of Well-being is used to discuss on the coping strategies used by the participants to deal with the grief.

Positive Emotion

- In this section, it relates to the experience of positive feelings and emotions, such as satisfaction, awe, joy, and contentment. The participant expressed how being in nature created positive emotions that helped her feel calm.

Right now, I like walking around, spend time in the nature sebab doing that, dia bagi minda I tenang (Siti).

(Right now, I like walking around, spend time in the nature sebab doing that, it makes me at peace)

Engagement

- Relates to the experience of flow and being consumed in an activity and environment. The participants engage themselves in other activities such as taking pictures, cooking, and writing out their feelings. By doing activities that were once enjoyed by the deceased parent, the participants felt closer to them. Besides, doing something out of spite, such as studying, is more prevalent among participants whose quality of life was negatively affected by their parent's death.

I think I put a lot of my energy into studying, because I don't want to end up here... studying can help me achieve a better life (Ann).

I write, yea... he has this notebook, there's still a lot of blank pages left. So whenever I miss him, I just write in the book (Chee).

My father's hobby, I jadikan ya my hobby. Kan my father memang suka ambil gambar and post kat Instagram, and I try to do the same la. So yea, my coping mechanism is like, capture every moment (Aisyah).

(I made my father's hobby into mine. He likes taking pictures and post them on his Instagram and I try to do the same. So yea, my coping mechanism is like, capture every moment).

I masak. Sebab dulu, I selalu dengan my mum dekat dapur and she taught banyakla pasal masak-masak ni. So, kalau I rindu dia, I masak masakan dia pernah ajar I dulu and bila makan tu, jadi teringat, and bila duduk atas meja and makan, seakan-akan dia pun ada kat situ juga. So, terubat la juga rindu tu (Siti).

(I cook. I used to cook with my mum and she taught me a lot about cooking. When I miss her, I cook the dishes she has taught me. When I eat them, it reminds me of her, Sitting and eating on the dining table, it feels like she is there as well. So, it cures the yearning).

Relationships

- Refer to the quality and quantity of social connections inside and outside of the immediate group. The participants bonded with their friends in times of grief and found comfort in their friends' support. Ann mentioned that their bonds are still as strong although most of them went separate ways after secondary school. Besides, Chee's bond with his friends is so close that his friends manage to visit his sick father. Therefore, Chee was able to receive decent emotional support during the care and after his death.

My friends masih, sampai sekarang sebab one of them pun sambung di UNIMAS tapi tidak sama course. And I am grateful, especially to my friends for their support, emotionally and physically (Ann).

(I'm still friends with my friends because one of them is also pursuing her study in UNIMAS but in a different course. And I am grateful, especially to my friends for their support, emotionally and physically).

My best friends know, eventually I have to let it out too. Thankfully they were always there for me during that period... Sometimes they would visit my father too, since the three of us has been friends since primary school, so we know each other's families (Chee).

Meaning

- Relates to something important to having a sense of purpose or meaning in life. The participants recognised the presence of hope in their lives after their parents' deaths which emerged in the form of family relationships. This was experienced by Ann and Aisyah, and it made them aware of the support that they have and consequently realised the bigger meaning behind their parents' deaths. Meanwhile, Siti who gained life-changing information about her condition finds meaning in living her life to the fullest while she still can. Overall, the participants were exposed to the need to appreciate their lives and the people they love more.

I would help myself... tell myself that this all happens for a reason. Sebab apa yang jadi ni tunjuk kepada saya siapa yang betul-betul care, and those are my friends, my ex, family... walaupun mereka bukan orang baik, mereka tidak support saya the whole time, tapi mereka ada bila saya perlu. And I would tell myself to appreciate them more and I am not the only one struggling, my mother, my siblings, semua struggle. So ya, itulah (Ann).

(I would help myself... tell myself that this all happens for a reason. Because what happened to me show to me the people who really cares, and those include my friends, my ex, and my family. Although they are not good people and they did not support me the whole time, but they were present when I needed them. And I would tell myself to appreciate them more and I am not the only one struggling, my mother, my siblings, all of us are struggling).

Better la I think (overall relationship with family and others). Contoh, macam my mum tek kan, dolok I sik selalu kelaka ngan nya but after my father passed away, I jadi makin sayang la dengan nya. And to my friend pun, I try to be there for them, mun macam sidak ada masalah ka, at least jadi listener for them (Aisyah).

(My overall relationship with family and others become better. For example, my mum doesn't really talk to me before until my father passed away so it made me love her more. And to my friends, I try to be there for them, be a listener for them if they ever have any problems).

Since I basically tau how my life might end kan, I jadi macam... tau tak dalam movie bila the main character tau yang dia orang tak hidup lama lagi and they start doing bucket list kinda thing? Yes, that's what I'm doing now (laughs). Walaupun like the cancer belum merebak lagi, which I hope not, I jadi menerima the things that I will lost (Siti).

(Since I basically know how my life would end, I see myself as a main character in a movie where she started doing busket list after knowing she won't be living for long. Although the cancer has not spread yet, which I hope not, I accept the things that I will lost).

Accomplishment

- Based on the experience of achievement and progression toward goals. The participants expressed their aspirations after their parents' deaths and are currently working through it. These aspirations come in different forms— Chee mentioned how he is trying to let his father live through him because they look alike while Kenneth recognised the need to gain appropriate healthcare skills and knowledge in order to provide quality care that includes both physical and emotional care.

People say I look like him, so I'm trying my best to live so that people could remember him all the time (Chee).

Taking care of my mother makes me realise that if I had the skills or knowledge at least, maybe I can provide a more quality care for her, because it's not only about taking care of her physical health... like if she receive good physical care, then she also can receive good mental and emotional care (Kenneth).

4.2.3.2 Kübler-Ross 5 Stages Of Grief

Following the PERMA Model Of Wellbeing, the Kübler-Ross 5 stages of grief is also used to look into the experience of grief went through by the participants.

Denial

- Denial is the first stage of grief discussed in Kübler-ross 5 stages of grief. The participants could be seen as not being able to accept the death. There was a moment of questioning whether it would be the end of their parents' lives after battling long enough with the illnesses as experienced by Aisyah. The unexpectedness of the death while the participants were involved in other activities or were physically absent during the time of the death also caused denial. Besides, Siti mentioned that professional help was ineffective because she was still heavily in denial about her mother's death.

Waktu ya kan kerja, kerja Boost time ya, WhatsApp notification masuk, 'bapa masuk hospital', nangis teruk... macam, 'tok kah jadi nya?' Banyak la pikir time ya, macam 'tok last ka?' tapi sik mok last (Aisyah, after knowing her father got admitted to the hospital).

(I was working when I received a WhatsApp notification saying my father had been admitted to the hospital. I cried so hard. I was thinking, 'is this it?' There was a lot on my mind at that time, 'is this the end?' but I did not want it to be the end yet).

Maybe sebab masatu I masih in denial kan (about the death), so for me tak membantu sangat (the counselling session) (Siti).

(Maybe because I was still in denial about my mother's death, hence the counselling session does not do much for me).

I was very sad, sebab saya tak expect dia untuk pergi secepat itu. Lama untuk saya proses yang dia dah pergi, sekarang tinggal saya berdua dengan kakak saya jak. I lost my father, I lost my mother... macam saya sudah tak tau nak buat apa, saya tak tau nak rasa apa sebab dalam sangat sakit tu, kesedihan tu, dalam sangat (Regina).

(I was very sad because I wasn't expecting her to leave that soon. It took me quite some time to process that she's gone and I am left with my sister only. I lost my father, I lost my mother... I don't know what else to do and feel because the pain and sadness was too deep).

Anger

- Instead of blaming the illness, the participants blame their deceased parent for not taking care of themselves. The participants described that since they had less information about their parents' illnesses, they were unable to persuade them to go to the hospital. It also angered them because their parents are adults who should have more rationality and having such illnesses should call for hospital check-ups.

Mun kita pergi sekolah nak, adala distracted dengan belajar so kita sik fikir gilak pasal emotion tapi bila balit sekolah, sedih, marah, semua la I think I rasa time ya. Lagi-lagi sebab nya sik mok pergi hospital kan, kita sebagai anak sik dapat juak mok polah apa-apa (Aisyah).

(I was distracted with studying when I went to school, so I did not think too much about my emotions but when I got home, I felt everything from sad to angry. What made it worse was that he himself refused to go to the hospital to check on his condition so as a daughter, I could not do much).

Jadi, for me, kalau dia bagitau saya yang dia sakit, mungkin saya at least dapat tolong dia (Regina).

(If she had told me that she was in pain, I could have at least help her).

Bargaining

- The in-depth interviews found that the participants tried to spend more time with their sick parents to make use of the remaining time they have. Chee said that although the fact that his father would pass away at certain times was vague, he made sure the time was used to the utmost. Hence, when the participants were not able to do so, they felt guilt and regret as experienced by Aisyah.

I think after my father was diagnosed I am trying to get ready for the real loss... spending more time with him, although I did spend a lot of time with him, with my brother together, but I try to be around him more, talk to him about random things (Chee).

Sebab I SPM juak kan, so my focus memang direct to SPM instead of my dad so, ada lah penyesalan di situ sebab kurang memories (Aisyah).

(Because I was going through SPM, my focus was directed towards preparing for SPM instead of my dad, so there is a little regret because I did not have a lot of memories with him).

Depression

- In this stage, the participants reported feeling helpless as they started to accept the reality that their loved one was not coming back. Chee, who is the eldest sibling felt the void was noticeable especially since he lost someone that should guide him in life as a son. Meanwhile, Siti's grief was very prominent to the point that her change in appetite caused her to lose so much weight. Regina described her grief as being sorrowful especially because the death was very sudden, and she could not be by her mother's side the moment it happened.

I just realised how much I miss him. I try not to think about it too much but I felt the loss the most when I needed his help as a son (Chee).

It took me quite some time juga (the grief to subside). The whole year after she passed away I was still grieving and I notice my berat badan banyak turun sebab I takda selera makan (Siti).

(It took me quite some time for the grief to subside. The whole year after she passed away, I was still grieving and I noticed my weight decrease a lot because I had no appetite).

Saya rasa macam takda semangat lagi nak hidup, knowing that saya dah jadi anak yatim piatu, tak sempat pun nak balas balik jasa mereka. Memang saya rasa hidup saya tak bermakna lagi, ... the fact that dia tinggalkan saya dengan tiba-tiba, masa saya takda kat situ dengan dia, buatkan saya rasa lebih sedih (Regina).

(I don't have any more will to live, knowing that I have become an orphan. I have yet to repay their deeds. I felt like my life was meaningless... the fact that my mother left me so suddenly, when I was not there with her, makes me sadder).

Acceptance

- Lastly, the participants learn to let go and live life without their loved ones. They also start to invest in family relationships and friends. There was also the realisation that there was nothing much that they could do to save their parents anymore and hence, they were able to come to terms with that reality as mentioned by both Chee and Kenneth.

Something in me told me that I'm not ready for his death but there is nothing I can do to prevent it, so I try to be with him all the time (Chee).

Or maybe I don't feel that much because I already spend a lot of time taking care of her, it's like she is spending her last moments with me and watching her go in my hand made me realise that I had done everything I could, so I can let her go willingly (Kenneth).

4.2.3.3 Religion

Expression of grief

In this subtheme, religion is discussed on how it is used as a coping strategy to deal with the grief. From the interviews, the participants reported praying for their loved ones and for themselves. It helped them find comfort and relief through the hard times especially because most of them did not talk about their grief to their families and friends. Besides, Kenneth and Justin revealed that the grief was the one that made them find their religion again as they started to accept the death and let go of the pain that came with it.

Yes, membantu. Sebab I sik kelaka the topic with my family but I kelaka dengan Tuhan. So, ada peace ya (Aisyah).

(It helps a lot. I did not talk about the topic with my family but I talk to God, so I found peace).

I would say, the reason I started to let go of everything is because of God, the hatred, the anger, it's bad? It's a sin for you to feel that way towards your own mother (Kenneth).

Berdoa... berdoa untuk my mum, berdoa untuk diri sendiri supaya tidak terlalu terbeban dengan rasa sedih, saya boleh let go my mum, supaya dia boleh tenang di sana (Regina).

(I pray for my mum, myself so that I am not too overwhelmed by sadness, so I can let go of my mum, so she can be at peace).

I feel like I become more closer to God, in a way that instead of asking Him to give me this, give me that, I just pray that He would bless my life with whatever is best for me (Justin).

CHAPTER FIVE

DISCUSSION, LIMITATIONS, IMPLICATIONS, RECOMMENDATIONS, AND

CONCLUSION

5.0 Introduction

In this chapter, the researcher will discuss the research findings by relating them with previous studies and theories. The researcher will also discuss the limitations of the research, its significance, implications, and provide recommendations for future research.

5.1 Discussion

5.1.1 Risk factors of grief in adolescents after parental death due to long-term illness

Adolescents who experience parental death due to long-term illness are exposed to the lack of expression of grief due to the absence of grief communication with family members. The in-depth interviews revealed that the participants did not talk about the grief and the deceased parents to their family members. The grief was also kept hidden as a way to minimise the inconveniences of having to deal with emotions alongside daily routine, especially for participants who came from a low-income family. These findings correspond to a study done by Li et al. (2023) where the participants were unable to express their grief as a way to protect the family's feelings. The current research found that the eldest siblings had difficulties sharing their grief because they had to take care of their family and handle funeral services. As a result, they were 'parentified', prioritising others' needs above their own. Thus, they had a hard time opening up and asking for help from other people. Similarly, Farella Guzzo & Gobbi (2021) touched on the possibility of 'parentification' of adolescents and how they may not be able to

acquire freedom going into adulthood as they are stuck becoming surrogate parents for their families.

Besides, the current research reported that the relationship between the deceased parent and the adolescent affects the intensity and the timing of the grief. Negative family relationships, such as having divorced parents and emotionally absent parents contributed to how the grief was described to be complicated rather than just difficult and tough. Consistent with prior research by Smigelsky et al. (2019), the findings in this research proved that the more conflicted the relationship before the death, the bigger the chance of unfinished business or unresolved tension exhibited in the form of grief severity such as emotional numbness and difficulty accepting the loss.

In addition, adolescents' relationship with their other family members after the death explains why grief was unknown to them. Specifically, negative relationships among family members such as taking less care of each other after the death, contribute to negative emotions such as anger and disappointment which lead to fewer interactions in daily life. As a result, the participants were not able to talk about their thoughts and emotions after the death. This is supported by a study which showed that the surviving parent is also going through bereavement at a different level, hence affecting the capability of giving emotional support to their children (Birgisdóttir et al., 2019).

Participants who lose their parents at a young age when they are mentally developing reported experiencing grief later in their lives. There were also mixed emotions on wanting the dread of taking care of their sick parents to end but realising that that would suggest wanting their parents to be dead, which the participants struggled with. Hence, they were unable to grieve during and after the death but experienced anticipatory grief due to the thought. These findings are in line with a study by Asgari & Naghavi (2019) which revealed that adolescents

experiencing paternal loss through sudden death exhibited initial confusion regarding the concept of mortality. Being exposed to traumatic life experiences at a young age exposed the participants to strong emotions unknown to them at the time. The participants explained that grief is a new experience and therefore, they never realised what they felt until they were old enough to understand it. This finding is similar to Pacaol (2021), in which the participants were aware of their loss. However, participants who lost their parents during early adolescence experienced more complexity in dealing with the grief in which they either were nonchalant about it or were stuck in extreme emotional distress.

5.1.2 Challenges and effects of parental death on adolescents' well-being and throughout their adulthood

Having experience taking care of sick parents and losing them at an age where they are still developing explains the participants' struggles with regulating their emotions. Intense sadness about the death is found to be the subsequent response after shock. Findings from Cafferky et al. (2018) are reflected in this research in which adolescents observing a parent's deteriorating health leads to confusion, anxiety, and distress especially as there are changes in their physical bodies. Adolescence is a development period where changes occur emotionally, mentally, and socially. Thus, the grieving process also involves intense emotions, often accompanied by confusion about what is happening in their life. The in-depth interviews found that the participants experienced sadness but tried to hide their feelings. Findings from Li et al. (2023) indicated that hiding sadness is common as a way not to trigger family members' emotional distress after the death.

Following the impact of relationships between the deceased parent and the adolescents, guilt is often felt by adolescents who did not manage to fix their relationships with their

deceased parent. This is caused by factors such as anger and disappointment towards the deceased parent for not taking care of themselves, broken family due to divorce, not appreciating the remaining time they had with their deceased parents and being relieved that their parents passed away. Parallel with findings from Lytje & Dyregrov (2019), guilt is still an overlooked psychological reaction to grief, and it depends on how the grief is expressed. If the grief is openly exhibited, there is a possibility of less guilt felt by the participants.

Besides, the participants also expressed resentment towards the deceased parent for reasons such as above, and towards their family members for putting off the responsibility solely on them. The participants struggled with the inability to enjoy their adolescence life like other adolescents and taking care of the sick parents required a lot of physical and mental effort. Consequently, it puts a load on adolescents' mental development which explains the feeling of relief they felt when their sick parents passed away. However, there is still very limited literature to support this claim. Tang & Li (2019) suggested that feeling relief is a form of rationalising the death, that the sick parent does not have to feel pain anymore once they pass away. Not only does taking care of the sick parents lead to emotional struggle, but it also puts strain on the physical body where the participants reported being exhausted and having changes in appetite. Changes in behaviour such as becoming hot-tempered and being quieter and more reserved were some of the observable changes in the participants. Hence, any traumatic life events that hugely alter their perception of life could easily impact their demeanour, as well as their beliefs and values. These findings are similar to those in a study conducted by (Lytje & Dyregrov, 2019).

Losing a parent, especially the main breadwinner of the family also puts the adolescents at risk for financial struggle. The participants who did go through the struggle describe themselves as being financially aware at a young age. In line with findings from Lytje & Dyregrov (2019), the loss of the main or the only breadwinner in the family can have a

disastrous impact on living conditions and social support. However, some of the participants disclosed that struggling financially increases their motivation to finish their studies, graduate on time, and find stable jobs that can provide for both them and their families.

Aside from the negative changes that have been discussed, losing a parent as adolescents allow the participants to be more appreciative of life and the people they care about. This is because having experienced loss at an unexpected stage in their life opens a perspective that loss is inevitable and could happen anytime soon. Consequently, having a stronger bond with family is the most prominent change undergone by the participants. Specifically, the participants reported becoming closer to their surviving parents. Therefore, it also becomes the reason why they are more motivated to be successful in life to make their surviving parents happy. Similar to findings from Farella Guzzo & Gobbi (2021), the increase in motivation is due to the fact that adolescents become more resilient as there is a need to be mature, independent, and have autonomy in their own life choices.

5.1.3 Coping strategies for grief in adolescents after parental death due to long-term illness

5.1.3.1 PERMA Model of Well-being

The PERMA Model of Well-being is applied as a coping strategy for grief in adolescents after parental death due to long-term illness. The adolescents managed to see the positive sides of their parent's death and thus, tried to cope with the grief in a healthy way. Aligned with findings from Laakso (2023), the use of positive psychology increased the positive affect of participants, particularly on the level of loneliness. While the changes may not be drastic, grief interventions are beneficial for participants to practice mindfulness and not let the negative emotions of grief take over (Laakso, 2023).

1. Positive Emotions

- a. The first and most essential step in dealing with grief is to experience positive emotions whether it is through activities or being around people that bring joy and contentment. By having positive emotions, the participants can reduce the emotional strain caused by overwhelming emotions, which can also promote hope and optimism for the future (Seligman, 2002). As a result, it allows the participants to believe in the ability to heal and move on.

2. Engagement

- a. Engaging in activities provides distractions and a temporary escape from the negative emotions caused by the loss. Hence, it allows for emotional regulation by shifting the participants' focus to the present moment. Specifically, engaging in hobbies allows the participants to connect to a happier version of themselves as they do what they enjoy as also found by Seligman (2002). Not only that but engaging in new activities or social groups opens the doors for new relationships which could be beneficial in building a new support system.

3. Relationships

- a. Having a good support system is important for emotional and physical support. Aside from offering a safe space to express emotions openly to make the participants feel validated, a strong support system can help reduce loneliness and provide a sense of belonging during hard times (Laakso, 2023). In addition, a good support system provides tangible assistance during overwhelming times, especially in being physically and emotionally present when needed.

4. Meaning

- a. Grief often raises existential questions on life and death. Finding meaning in the storm develops a narrative about the loss which can create a better understanding of life's purposes. Seligman (2002) suggested that finding meaning promotes personal growth by turning negative experiences and the inability to get proper support from family members into being a bigger person. This includes being more appreciative of oneself and others and using the grief as a drive to be a more compassionate person.

5. Accomplishment

- a. After trying to find meaning through the grief, the participants worked towards the meaning which resulted in changes in personal values and beliefs, as well as in skills and knowledge necessary to become a better person. These findings are similar to those of Seligman (2002) in which setting goals that are attainable yet challenging and achieving them help to flourish life together with other components of PERMA.

5.1.3.2 Kübler-Ross 5 stages of grief

Kübler-Ross 5 stages of grief is used to discuss adolescents' experiences on grief about losing their parents to long-term illness. Understanding the experiences that they go through in each stage provides a better understanding of their suffering. Subianto & Winardi (2023) who have conducted a similar study explained the journey of grief through Kübler-Ross 5 stages of grief, with a little addition of a sixth stage called 'finding meaning'.

1. Denial

- The participants went through emotional turmoil and were unable to accept the reality of the loss. This feeling came with feelings of numbness and helplessness, which resulted in avoiding healthy coping mechanisms. Similar to findings from Subianto & Winardi (2023), denial is said to be a form of defense mechanism that protects the mind from acknowledging the loss has happened.

2. Anger

- Anger manifested in grief as irritability, anger directed towards the deceased or the world, and anger towards oneself (Subianto & Winardi, 2023). The participants specifically felt angry towards their deceased parents for not taking care of themselves. The participants also blamed the deceased parent for not telling them about their sickness, which hindered them from getting help and worsened their conditions.

3. Bargaining

- The realisation that their parents would not live long enough caused the participants to bargain with time. They started to spend more time with their sick parents and taking care of them. This is because bargaining created a glimpse of hope that the death could be stopped or altered if they took care of their parents enough. Hence, they felt guilty for not doing so sooner after their parent passed away (Subianto & Winardi, 2023).

4. Depression

- In this stage, participants reported feeling intense sadness, loneliness, and a sense of loss. There was also an observable change in appetite which caused weight loss, hopelessness to continue living, and the longing that came along (Subianto & Winardi, 2023). Despite the grief being painful in this stage, it allows for deep emotional processing which can facilitate meaning making to aid in the healing process.

5. Acceptance

- Acceptance does not signify forgetting the loss or feeling happy about it. It represents a shift in the participants' relationship with the loss instead. This is shown through accepting the reality that there is a permanent loss in life and does not resist the change. Subianto & Winardi (2023) suggested that acceptance is not about being content with the loss but coming to terms with it and the new reality without the deceased that will take place. While sadness can still be a prominent feeling, it is not too overwhelming that it affects daily functioning anymore. The participants were able to go through the acceptance stage by acknowledging that death is inevitable and while taking care of their sick parents, they were able to spend the remaining time with them and therefore, provide closure to their inability to save their parents from the illness.

5.1.3.3 Religion

Throughout their grief, the participants did not go for any professional help except for school counselling as reported by one of the participants. Following the nature of her school being a religious school, the counselling relies highly on using religion as a coping strategy.

The participants' religion and beliefs help them cope with grief by providing a space between themselves and God to seek comfort and solace. The participants shared that praying allowed them to express their emotions without prejudice and they were able to let go of negative feelings and thoughts. It also helped them to have a sense of forgiveness towards their deceased parents and promote hope and renewal which focuses on moving on towards better things and becoming a better person in the future. Although some participants went through questioning the beliefs of their religions, they eventually returned to their faith (Mosher, 2018).

5.2 Limitations of study

This research has come across some limitations recommended to be addressed in future research. Eight participants served as a typical IPA sample size. However, an expanded sample in terms of number and diversity is recommended. This is because a small sample size consisting mostly of participants from Sarawak could not represent all adolescents and university students. Besides, the findings of the study are limited to the research participants only as this is a qualitative study. Moreover, the sensitivity of the topic often resulted in long silences especially since most of the participants had only managed to express their grief during the interview, and thus, require the researcher to be more proactive in contributing to the positive flow of the interview. This may have also resulted from the setting of the interview, in which most interviews were done online due to the restriction of time and place— the interviews were done during semester break when students were physically away from UNIMAS. Not only that but the possibility of a recall bias could also affect the findings of this study. This is because the participants needed to recall events from many years ago which could be distorted. Besides, there is a risk of information loss that can occur from connection loss and faulty online storage. Finally, there is also a limited number of recent literature and research on

grief in adolescents in Malaysia which could not provide enough evidence to support the current research.

5.3 Implications of study

The findings in this research demonstrated the experience of adolescents in dealing with grief after parental death, the risk factors, challenges and effects of parental death on adolescents' well-being, and the coping strategies managed by the adolescents in dealing with their grief. Results from this research provide important implications for public awareness as grief in adolescents is often overlooked. When there is an increased awareness on this matter, support from parents and family members especially in communicating the grief openly among each other can be practiced. With this, it fosters a sense of belongingness in the family, aiding in the healing process. Besides, public awareness on grief could assist in tailored interventions. This includes more age-appropriate grief counselling programs or peer support groups catered to adolescents. Consequently, adolescents could find peers who went through the same traumatic experience and are able to find support through the hard times.

In addition, results from the current research bring forth the manifestation of grief during adolescence in adulthood, focusing on the long-term effects of emotional trauma on adolescents' well-being. Not only that, but findings from this research could help in informing how culture affects grieving experiences and the urgency for the development of culturally sensitive grief support programs for adolescents from various backgrounds.

5.4 Recommendations

In future research, exploring different sociodemographic of participants is highly recommended to increase information regarding grief in different life phases and cultures.

Besides, future researchers must take into account the complexity of talking about grief. Hence, they must equip themselves with the skills and knowledge necessary to touch on the topic. Considering the topic's sensitivity, conducting physical interviews with the participants is also advised. This allows the researcher to create a safe and reassuring environment for the participants to share their grief comfortably. Finally, a longitudinal study shall be considered by future researchers to observe grief reaction over time which can yield more accurate and high-quality findings.

5.5 Conclusion

The current research shows adolescents dealing with long-term illness in parents and witnessing their death at a young age was a traumatic experience that altered their perspective on life and death. This is because parental death is outside the natural order of childhood experiences and considering that adolescence is a period of crucial mental and social development, the absence of a parent who is supposed to guide adolescents into their adulthood could disrupt the process. This study has shed light on the intricacy of grief in adolescents in Malaysia. Although there has been an increased interest in grief studies, there is still not much being done on adolescents and just how significant and traumatic the grief is to them. The small amount of research being done in the context of Malaysian adolescents is also incapable of providing enough information to confirm and expand the newly acquired knowledge. It should also be notable of the impact of grief on adolescents' well-being and finding the right support is essential in making sure they do not suffer from the negative long-term effects of grief. Lastly, the findings of current research hope to share that grief is an unavoidable phase and that healing is a gradual individual process. Therefore, focusing on healthy coping strategies could promote better life perspectives and increase positive well-being in adolescents as they move through life.

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APPENDICES

Appendix A: Participant Information Sheet



Participant Information Sheet

Dear Participant,
Please take some time to read through the following information.

Research Title

Exploring the Psychological Well-being of Grieving Adolescents Following a Parental Death Due to Long-term Illness.

Research Purpose

I am from the Faculty of Cognitive Sciences and Human Development in Universiti Malaysia Sarawak (UNIMAS). I am interested to study about 'Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness.' Therefore, I would like to invite you to take part in this study and share your experiences, that you think is relevant regarding this matter.

Your Role

If you agree to be a part of this study, you will be involved in an interview session that may take 1 to 2 hours of your time. However, the time allocated for the interview depends on you and we can set the time and place according to your liking.

Participation Agreement

Your participation is voluntary, and you have the right to withdraw yourself from the study anytime you want. I will be recording the interview session and once it has been transcribed, the information will be destroyed. I will not disclose your name or any other private information that can reveal your identity in any records and information that we will use in this study.

Confidentiality

All your information is guaranteed confidentiality and I am the only one to know your participation in the study. I will be using your information for the study's findings, report, and presentation. However, I will make sure that the information used will not reveal your name and it stays confidential. This includes extracts written in the article and during the presentation.

If at any point you have any questions, please do not hesitate to ask the researcher, Natasha Norina Anak Rawlin or contact me at 016-8649061 or email me at 78305@siswa.unimas.my. You can also contact the supervisor of this study, Dr Jamayah Saili at 019-8127274 or email her at sjamayah@unimas.my.

I highly welcome your cooperation and participation in this study and appreciate your sharing of experiences. Thank you.

Appendix B: Informed Consent Form



Informed Consent Form

**Grief in Adolescence: Psychological Well-being of University Students
Following Parental Death Due to Long-term Illness**

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature :  _____

Date : 29/2/2024 _____

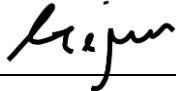


Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : 

Date : 1/3/2024



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : Aesha

Date : 5/3/2024



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature :  _____

Date : 15/3/24



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : shy

Date : 22/3/2024



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : beleak

Date : 28 Mar 2024



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : _____

Date : 2/4/2024



Informed Consent Form

Grief in Adolescence: Psychological Well-being of University Students Following Parental Death Due to Long-term Illness

Please ensure that you have consented to the followings before being interviewed:

- I understand the purpose and procedures of the study
- I was given the participant information sheet beforehand
- I understand that my participation is voluntary
- I understand that my name, address, and other private information will not be used
- I understand that my answers and reactions will be kept confidential
- I agree and consented to be a part of this study
- I agree and consented for my interview session to be recorded for the use of this study

Signature : _____

Date : 23 April 2024

Appendix C: Guided Questionnaire

Demographic	Which parent passed away?
	Reason for the parent passing (What illness do they suffer from?)
	When did it happen? / At what age did your parent pass away?
	How long has it been since your parent's passing?
	How many siblings do you have? / Order of siblings
	What is your family's economic status?
	At what age do you know about your parent's illness?
	What did you feel when you knew about your parent's illness?
Risk factors	Is there any change of behaviour you see in yourself? (during taking care of the sick parents and after their death)
	Did you seek any professional help/taking medication after the death that you did not before?
	Did you talk to your family/friends about your feelings?
	How does the death of your parent affect your family relationship?
	Do you notice any changes in your surviving parent? What are they? How do the changes affect you?
	Were you struggling after the death? (emotionally, physically, and economically)
	How was your relationship with your deceased parent?
Effects of grieving on psychological well-being	How do you see your life after the death?
	How long did it take for the grief to subside?
	Do you have difficulty having positive emotions after the death?
	Did you get to express your grief openly?
	Was there any difference in your school performance?
	Do you remember what you felt back then when you were still an adolescent?
	Did any of your behaviour change after you know about your parent's diagnosis?

	How would you feel if your parent passed away now (as an adult) instead of back then? Would your feelings and reactions differ?
	How does it feel to leave your family for studies after your parent passed away?
Coping strategies	Do you receive any social support during and after the death? If yes, from whom and in what ways?
	How do you overcome the negative feelings from the grief?
	Does your faith and religious belief help in coping with the grief?
	Do you notice any positive changes after the death?
	If you were given another chance to see your deceased parent, what would you say to them? / What would you do differently?
	As an adult now, how would you help your younger self during that time?
	Any good memories that you will always remember?

Transcripts

Participant 1: Ann

Ann	Umm, I would say... ok jak. Because kalau nak kata bahagia tu tak juga, biasa-biasa jak. Sebab kami orang susah juga, so struggle tu sentiasa ada tapi fortunately, my uncle, my other family members ada tolong. Yang tu, saya memang berterima kasih dengan mereka.
Interviewer	Ahh, I see. That's good to hear your family are supportive of each other.
Ann	Yea.
Interviewer	Were you close with your father?
Ann	Umm, from what I remember, I don't think I'm close with him. Cause most of the times dia kerja, pergi pagi, balik malam, malam pun saya selalunya dah tidur. So, I didn't get to spend a lot of time with him.
Interviewer	How long did it take for the grief to subside?
Ann	Umm, actually... the grief hits me later. Not directly during the death. But also I think masa saya jaga dia tu, saya dah tau yang dia tidak lama lagi dengan kami, so masa tu saya dah grieving, berduka... so masa dia meninggal, saya tak rasa apa-apa. Saya just focus jaga rumah, jaga adik-adik, ya la kan sebab perlu ada orang atur makan minum untuk orang yang datang kan, saya pula anak sulung. Jadi, masa dia meninggal, jenazah dia di rumah, saya tak rasa apa-apa. After that, after my mum dah mula bekerja, saya rasa dibiarkan untuk buat tanggungjawab rumah sendiri, di situ yang saya rasa 'kenapa lah benda ni terjadi kepada saya?'
Interviewer	Do you still feel that way now? Questioning everything?
Ann	Yes, sometimes.
Interviewer	How so? How does the grief reappear?
Ann	Umm, I am a bit sensitive when I see a father-daughter moment in public macam tu? Because it makes me wonder, maybe I can experience that if he is not dead. But then again, I don't think I will be close with my father because of his nature: dia tak pernah cakap dia sayang kami, dia pun baran sikit. Umm, cuma, ya it would be nice to experience that...ada orang yang jaga. Maybe that's why I was so dependent on my boyfriend.

Participant 2: Chee

Chee	Yea, they are. For my mother, I could see that she was having a hard time but she try to cover it. We really were alone you know, back when this happen. We just have each other to rely on so I try to do anything she told me to, hoping that would ease her burden.
Interviewer	Did she tell anything to you? Maybe about what she felt?
Chee	No. But I hope she has someone she talked to.
Interviewer	Has you change in any way? After you know about the diagnosis and after your father passed away?
Chee	Hmm... I don't think I change that much. But I think I'm becoming more quiet... then again I am always quiet though, I don't really talk a lot.
Interviewer	Maybe not your behaviour but your perspectives, values, maybe... did they change?
Chee	Ahh, for that I would say yes. I think after my father was diagnosed I am trying to get ready for the real loss... spending more time with him, although I did spend a lot of time with him, with my brother together, but I try to be around him more, talk to him about random things. Something in me told me that I'm not ready for his death but there is nothing I can do to prevent it, so I try to be with him all the time.
Interviewer	Did you talk about the illness with him?
Chee	No... although we did talk about it, I wasn't the one who initiated it. Mostly the conversation would lead to me having the responsibility to take care of the family. Maybe he wanted to make sure I was ready, and that the time will come sooner for him to leave us.
Interviewer	How bad was the grief for you?
Chee	I'm not sure... I think it's pretty serious for me.
Interviewer	Did you cry during his funeral?
Chee	Yes, I try to hide it, console my mother and my brother but I ended up crying like them too... what to do, he's my father too, I love him as much as them.
Interviewer	Do you still cry about him after the funeral?

Participant 3: Aisyah

Interviewer	Okay, that's good to hear. So tadi you ada mention that you were there masa your father kena the first stroke nak? So, how did you feel back then? If you remember...
Aisyah	I don't remember. I just remember time nya first kena admit to hospital.
Interviewer	Okay, so how do you feel that time?
Aisyah	Okay, waktu ya kan kerja, kerja Boost time ya, WhatsApp notification masuk, 'bapa masuk hospital', nangis teruk... macam, 'tok kah jadi nya?' Banyak la pikir time ya, macam 'tok last ka?' tapi sik mok last. So, I avoid again. I sik padah ngan orang pun, I sedih sorang jak. Lekak dapat notification ya, obviously kamek orang pergi hospital la nak. Sedih la tengok nya macam ya tapi, sik juak la padah 'I love you' ka apa ka, macam mampu terdiam jak, macam sik dapat terima kenyataan lah.
Interviewer	Ada sik you have difficulty having positive emotions during nya sakit and after nya meninggal?
Aisyah	During nya sakit, adala challenges ya. Mun kita pergi sekolah nak, adala distracted dengan belajar so kita sik fikir gilak pasal emotion tapi bila balit sekolah, sedih, marah, semua la I think I rasa time ya. Lagi-lagi sebab nya sik mok pergi hospital kan, kita sebagai anak sik dapat juak mok polah apa-apa. Mun after, kan I padah I try to distract myself nak, so I think positive emotions okay jak lah. Unless, orang embak the topic again, topic 'bapa', tanya apa-apa pasal nya, mesti I sedih. Kiranya macam suppress the emotions, the thoughts, gia lah.
Interviewer	I see. umm... if lah nak, dapat putar balik waktu, apa yang you akan polah untuk tolong nya?
Aisyah	Apa yang I boleh polah I think, always be there for him la. Kan I distracted dengan SPM nak, but maybe if sikda SPM ya, I would give my 100% attention to him. And then, kurang marah nya la, ya sigek juak. Because bila marah nya, kita sik dapat mok padah kita sayang nya nak so part ya annoyed sikit. Tolong nya... sebab contoh, I fikir hari tok mok tolong nya makan, tapi sik polah pun. So, mun dapat putar balit masa memang I akan tolong nya lah.

Participant 4: Kenneth

Interviewer	Do you receive any sort of social support during or after the death?
Kenneth	Social support I would say from my older sister. She's the only one keeping me mentally and emotionally in check.
Interviewer	Did she know about your feelings towards your mother too? The anger and everything...
Kenneth	Yes, she knows. Because she also feel the same way, but she just let it go, not like me. So, I think she understands me, so that's why even though I didn't tell her about it, but everytime we talked about it she somehow knows how I feel, even while taking care of my mother, she always ask if I'm okay, if I can endure my feelings. But because I don't want to menyusahkan, I just said I'm okay.
Interviewer	How did you feel leaving your family for studies after your mother passed away?
Kenneth	Nothing much, but I felt kesian to my older sister because she has to be our 'mother' now... my younger sister is staying with her also. I don't feel anything but I know my younger sister feel the loss more because my mother was her main support system, and she passed away during her SPM year. I feel bad for her because I couldn't support her physically, but I always hope that she's okay. But now we are studying in the same area so I always ajak her to keluar makan.
Interviewer	Do you have difficulty having positive emotions after the death?
Kenneth	I already had difficulty even before the death, especially after the divorce. Now I'm letting go everything, and just try to appreciate the people that stays, like my siblings.
Interviewer	Do you notice any positive changes after the death?
Kenneth	Like I mentioned just now, more appreciative of my siblings.
Interviewer	Do you always wanted to study nursing?
Kenneth	No. but taking care of my mother makes me realise that if I had the skills or knowledge at least, maybe I can provide a more quality care for her, because it's not only about taking care of her physical health... like if she receive good physical care, then she also can receive good mental and emotional care, if you know what I mean.

Participant 5: Siti

Siti	At that time I selalu juga chat, call, meluah dengan my friend. Takdala meluah apa pun sebab my family ok je, cuma I je yang rasa kosong... my family pun ok je tanya khabar, jaga makan minum... tapi tula sebab sedih dengan rindunya yang buat I macam takda semangat nak hidup.
Interviewer	Teruk ke? I mean... apa yang you rasa masa tu teruk sangat sampai ada affect your daily live, daily functioning...?
Siti	Umm... after my mum passed away, seminggu I tak keluar bilik, I kunci pintu, I nangis apa semua, sumpah memang teruk I nangis masa tu, my dad sampai perlu pecahkan pintu bilik, my brother yang dah kahwin tu, dia duduk Johor, my dad terpaksa call dia suruh balik sebab...(mengucap) my dad dah tua dah time tu, dah masuk 60 years old, ya Allah rasa bersalah sangat bila ingat balik. I memang fikir diri sendiri je time tu. After that, I memang takda selera nak makan, seminggu tu jugala I tak datang sekolah.
Interviewer	You ada minta professional help waktu tu?
Siti	Actually my guru kelas yang recommend I untuk pergi counselling dengan counsellor sekolah sebab I seminggu, seminggu weh, tak datang sekolah and bila kat sekolah I memang selalu menyendiri and tak cakap sangat macam selalu. Sebab I jenis hyper tau, energetic macam tu, memang selalu bising lah, so bila orang tengok I macam tu, siapa je yang tak riasau kan? So, at that time, I ikut je sebab my dad pun risau so dia pun suruh I pergi je.
Interviewer	Membantu tak? The counselling...
Siti	Umm... maybe sebab masatu I masih in denial kan, so for me tak membantu sangat. Lagipun, the counsellor macam memberi nasihat to me, cakap 'janganla sedih' things like that... tak membantu pun sebenarnya (laughs). Tapi adala certain things yang I take in, macam suruh reda, dekatkan diri dengan Tuhan, doakan dia, lebih kepada pendekatan spiritual sebab I dulu sekolah kat sekolah agama.
Interviewer	Kiranya your beliefs and your religion tu yang membantu for you to cope with the grief?
Siti	Yes. Memang banyak membantu.

Participant 6: Regina

Regina	No, but I was wondering berapa lama lagi dia akan bertahan. I thought maybe a few more years, tapi ya... untuk dia pass away that soon, memang saya tak expect.
Interviewer	Did you have difficulty experiencing positive emotions after the death?
Regina	Ya, ada. Memang ada. I was very sad, sebab saya tak expect dia untuk pergi secepat itu. Lama untuk saya proses yang dia dah pergi, sekarang tinggal saya berdua dengan kakak saya jak. I lost my father, I lost my mother... macam saya sudah tak tau nak buat apa, saya tak tau nak rasa apa sebab dalam sangat sakit tu, kesedihan tu, dalam sangat.
Interviewer	Did you notice any change of behaviours in yourself after the death?
Regina	Yes. I become more quiet, more reserved, I don't really talk a lot after that, and I don't go out of my room, don't really join any activities di campus, memang saya menyendiri.
Interviewer	Did you talk to anyone about your grief?
Regina	No. I don't really talked about it.
Interviewer	Not even to your sister? Or maybe your friends?
Regina	No, because I think my sister dah banyak beban, sekarang dia perlu kerja untuk tanggung kami berdua, jadi saya rasa tak perlu la saya nak tambah beban dia untuk fikir pasal saya. And, I don't really have close friends di asasi masa tu, and most of my secondary school friends mereka sambung tempat lain. Tapi, untuk saya contact mereka pun, untuk cerita apa yang saya rasa... saya rasa yang mereka tak akan faham apa yang saya rasa. Because, when I tell them my mum sudah meninggal, mereka just kata condolence, kata 'you'll be okay, be strong jak', tapi saya sendiri pun tak tau sampai bila saya boleh okay, sampai bila saya tidak okay, sampai bila saya boleh jadi strong. Saya nak bercerita tapi always akan end up to the same statement, which makes me feel like mereka memang tidak faham, so tak nak la saya nak menagih simpati daripada mereka all time, mungkin mereka pun penat dengar.

Participant 7: Justin

Justin	Umm... like I mentioned just now, it was really physically and mentally challenging. But aside from my father himself, I feel like my environment and my family also contribute to the severity of the challenges. Like, for example, my sister, whenever she came back from Miri, she would always complain about the way I take care of my father, the kind of food I cook for him. She asked me to cook healthy food but my father pun usually complain that he want to eat normal food, the kind of food he usually eats before. So, I do it jak la because I don't want him to throw tantrum. But, then my sister said 'don't listen to him... he doesn't know his own condition', things like that. There, I just feel like she don't have the right to say that because I was the one taking care of him most of the time, and I know what his condition is like. So, I kind of hated it when she comes back because she always complain about things before she know what I have to go through first. And, technically, she didn't take care of my father directly, she's just there for financial support and give orders to me.
Interviewer	Do you talk to anyone about what you're going through?
Justin	Not really. But, I did talked to my friends just not everything.
Interviewer	Does that help?
Justin	At the time, yes. Because I can express everything but when I come home, I still feel the same thing. I just feel better temporarily.
Interviewer	What about after his death? Did you feel like anything changed?
Justin	I feel like I've become more distant with my family... emotion-wise. Because I feel like since I already express a lot of my feelings, my disappointment to them when I was still taking care of my father, there isn't a lot of things I wanted to say anymore. It's kind of ended there. And, they never really asked how I felt, if I'm tired, if I'm angry... all they know is that I have to take care of him, because they have other 'responsibility', as if I don't. As if I don't have school, I don't have exams. Eventually, I got fed up trying to talk to them so after my father passed away, I shut them out, in a way. I just stay in the house because they are all I had, especially since I still need money from them... I'm not financially independent yet.
Interviewer	So, would you say that your family relationship after the death got worse?

Participant 8: Natalia

Interviewer	Do you still feel that way now?
Natalia	I think I'm okay now, I can accept the fact that he's gone but sometimes I just miss him. When that happen, I usually go back to that phase, when either I'm not eating or when I'm eating too much.
Interviewer	Did your family notice that?
Natalia	I think they do but they don't say anything.
Interviewer	I see. Does binge-watching and eating help you to not feel sad and think about your father?
Natalia	Hmm... maybe? But I usually watch K-drama so that I can feel something. Not sure about why I'm eating so much though.
Interviewer	Then, is there any coping strategies for you to overcome the sadness?
Natalia	Umm... what I usually do is I don't really think about it, I don't really talk about him also.
Interviewer	Your family also don't talk about him?
Natalia	No... we don't really talk about him.
Interviewer	Why?
Natalia	For me, because what happened to my father was very traumatic and very sudden, the accident, the death... no one really see it coming. So, I don't have time to process everything and suddenly my life kind of turned upside down. My entire routine, my father, my family, my life, they all change altogether so it was very very hard for me. When I remember him, I also remember all the hard time we have to go through. My mother has to go back and forth to atur the insurance, we have my father's colleagues visiting, almost everyone that we know visited him and they all tell us to be strong. After that they're just gone, they don't visit anymore, not even my uncles and aunties, they kind of move on with life while we are still stuck taking care of him and hoping that he would get better. Also, for me I don't really want to remember how he suffered because that memory is very painful for me. It's painful to see that the person who is suppose to take care of me, my family terlantar jak. And sometimes, he cried but since he cannot move and cannot really speak, he just cried while I'm feeding him.