

Running Head: EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

University of Botswana

Faculty of Health Sciences

School of Nursing

Experiences of Caregivers of Children (6-13 years) with Chronic Pain in Scottish

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Abstract

Chronic pain is a common problem affecting many children around the world. Caregivers of children with chronic pain often experience significantly poorer health that often results in family dysfunction. Despite the negative health outcomes reported by some caregivers, some report great life satisfaction, less depression, and feel a sense of reward. There is a need to understand the nature of experiences of caregivers of children with chronic pain. The specific aims of this study are to explore the experiences of caregivers of children (6-13 years) old with chronic pain; to describe the challenges of caregivers and to explore the coping strategies used by caregivers. The study will use a descriptive phenomenological qualitative design. Ten participants will be purposively selected from caregivers for children with chronic pain in Scottish Livingstone Hospital, Molepolole. Ethical approval will be sought from Institutional Review Boards of University of Botswana, Ministry of Health and Scottish Livingstone Hospital. Data will be collected through semi-structured interviews. Emerging themes will describe the experiences of caregivers of children with chronic pain. The results will be used to develop programs that will enhance caregivers coping mechanisms and facilitate positive outcomes to improve psychological and physical wellbeing. Furthermore, the results will enhance development of new policies, and development of health-promotion strategies for children with chronic pain.

Keywords: Caregivers, children, phenomenology, chronic pain, coping.

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Declaration

This is a declaration that this proposal is my own work. All the sources quoted have been acknowledged.

Signature (Gomolemo Oodira)

Date:

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Approval

This study proposal has been examined. It is complete and approved as meeting the required standards for partial fulfillment of the requirements for the degree of Masters of Nursing Science.

_____	_____
Supervisor	Date
_____	_____
Internal Examiner	Date
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Director, School of Graduates Studies	Date
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External Examiner	Date

Chapter 1

Introduction and Background

Becoming a caregiver is a critical and important life-changing process. Caregivers are able to provide valuable interpretations of pain behaviors of those they are caring for. However, being a caregiver of a child with chronic pain is particularly a daunting and challenging role (Palermo & Eccleston, 2009). The myth and misinformation on young children experiencing less pain than adults has long been negated. Anand, Grunau, Oberlander (1997) revealed that children and adults experience similar degrees of pain. Hence, this qualitative study will elucidate the experiences of caregivers in caring for their children (6-13 years) with chronic pain.

Pain is a subjective personal experience expressed through verbal and non-verbal behavior and through the patient's attitude and beliefs (Biro, 2010). The International Association for the Study of Pain (IASP, 2006) defines pain as an unpleasant sensation and emotional experience associated with a real or potential damage to tissues or the equivalent of such damage. The IASP definition of pain focuses both on pain sensation and pain perception that may occur without any identifiable stimulus. In addition, the definition incorporates the psychological factors that can influence the experience of pain.

There are two broad types of pain namely; acute and chronic pain. The American Academy of Pediatrics (AAP) (2001) defines acute pain as one of the most common adverse stimuli experienced by children, occurring as a result of injury, illness and medical procedures. Acute pain is typically brief, ending around the time of the healing of an injury, or the termination of the stretching, contraction, or impingement of some part of the body (AAP, 2001; Cohen, MacLaren & Lim, 2007). On the other hand, chronic pain is a recurrent or persistent pain lasting longer than the normal tissue healing time, approximately three to six months (IASP, 2006; AAP, 2001).

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Children may experience chronic pain related to injury, e.g., burns or a chronic disease processes such as cancer, arthritis, chronic kidney disease, Sickle Cell Disease (SCD) and Cerebral Palsy (Parkinson, Gibson, Dickinson & Colver, 2010). Chronic pain may also be present without any specific, identifiable injury or disease, e.g., functional abdominal pain (Cohen, MacLaren & Lim, 2007). According to Ishizaki et al. (2012), chronic pain is a common symptom in pediatric practice that affects many children. The pain is reported to be severe, distressing, and disabling. However, chronic pain in children may be difficult to assess and treat (Tong et al., 2010) because children may not adequately describe the source or type of pain experienced (Azam, Campbell & Ross, 2012).

Children's experience of chronic pain is recognized as one of the most complex human stressor which may have consequences for later pain-related behavior and perception (Kortesluoma, Nikkonen & Serlo, 2008), and significantly interfere with the child's daily functioning (Vervoort, Huguet, Verhoeven & Goubert, 2011). Children with chronic pain depend on their caregivers to perform activities of daily living such as bathing, feeding and elimination. Parents as caregivers can also assess, interpret and report pain that children experience (Palermo, Valrie & Karlson, 2014).

Caregivers of children require considerable resources including time and money. These demands may affect the caregiver's health and ability to cope and influence the quality of care provided to children. In support, Brehaut et al. (2009) found that caregivers of children with chronic pain reported increased levels of stress, distress, emotional problems, and depression.

Despite the negative health outcomes reported by some caregivers, others reported great life satisfaction, less depression, a sense of reward even when the process of caregiving is demanding (Blum & Sherman, 2010; Pearlin et al., 1990). With more attention to caregiving of children with chronic pain, there is a need to understand the nature of

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experiences of caregivers of children with chronic pain. This information can guide healthcare professionals in finding ways to improve adaptation for caregivers of children with chronic pain.

This chapter will discuss the statement of the problem, significance, research questions and theoretical framework which will be used to guide the study.

Statement of the Problem

Chronic pain in children and is estimated to affect 20% to 35% of children around the world, and 8% of children are reported to experience severe and frequent pain (Ishizaki et al., 2012). Chronic pain is mostly reported in conditions that affect the head, stomach and back, and some children report more than one type of pain (Ishizaki et al., 2012; Haraldstad et al., 2011). A study in Kenya revealed that even caregivers of children with disability reported chronic pain on children (Geere et al., 2012).

Comparative studies have revealed that family as caregivers of children with health problems tend to experience significantly poorer health and family dysfunction, e.g., more conflict and less cohesion than families of healthy children (Brehaut et al., 2009; Palermo, Valrie & Karlson, 2014). Moskowitz et al., (2007) asserted that caregivers of children with SCD are burdened with missed work, increased family stress, and increased illness care demands.

Similarly, in one recent study on children diagnosed with chronic kidney disease, parents who were caregivers reported that they spent less time with their spouses and other children, had social restrictions and were unable to travel as a result of depleted financial reserves (Tong et al., 2010; George, Vickers, Wilkes & Barton, 2007). Two studies in Botswana revealed that caregivers experienced anxiety, emotional stress and physical exhaustion and socio-economic challenges related to their caring role for children (Trivedi,

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Sharma & Nnyepi, 2011). While these studies are few and focused on caregivers in general, little is known about the experiences of caregivers of children with chronic pain in Botswana.

There is need for an in-depth understanding in this area. This gap is problematic and warrants a further study. Therefore, the proposed study would serve as a preliminary study in Botswana to facilitate a search for the meaning of the experiences of caregivers of children with chronic pain.

Significance of the study

Caregivers of children with chronic pain experience recurrent negative outcomes, e.g., stress and grief (George et al., 2007). A major finding of a study by Haraldstad et al. (2011) is that some parents overestimate pain experienced by children. In addition, some families and children with chronic pain may perceive pain as a natural part of the underlying condition (Russo et al., 2008), and as a result, may not seek medical help.

The proposed study is significant as it will enhance development of new policies, preventive programmes and health-promotion strategies for caregivers of children with chronic pain. Families, parents, nurses, doctors, teachers, psychologists, and social workers will benefit from the findings in the provision of services to caregivers and children with chronic pain.

Research Questions

This study seeks to explore the following research questions:

- How do caregivers perceive care of children aged 6-13 years with chronic pain?
- How has caregiving impacted on caregivers of children 6-13 years with chronic pain?
- What are the challenges of caregivers of children aged 6-13 years with chronic pain?
- What are the coping strategies that caregivers of children aged 6-13 years with chronic pain use?

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Aim

- To seek an in depth understanding of experiences of caregivers of children 6-13 years with chronic pain.

Specific Objectives

The specific objectives are to:

- explore the experiences of caregivers of children 6-13 years old with chronic pain.
- explore caregiving impact on caregivers of children 6-13 years with chronic pain.
- describe the challenges of caregivers of children 6-13 years with chronic pain.
- explore the coping strategies that caregivers of children aged 6-13 years with chronic pain use.

Theoretical Framework

Lazarus and Folkman`s (1984) Transactional Cognitive Model of Stress and Coping.

The Transactional Model of Stress and Coping by Lazarus and Folkman (1984) will be used to explore in-depth analysis of the meaning of experiences of caregivers of children (6-13 years) with chronic pain. The study will provide a foundation on which to build an essential understanding of what it is like to be a caregiver of a child experiencing chronic pain. In addition, this study will provide pragmatic evidence that may be used to guide interventions to help caregivers reduce emotional distress related to caring for children with chronic pain.

Stress and coping process models have often been utilized in studies on caregiving to explore the individual differences in managing stressors that caregivers face and to predict physical and emotional outcomes (Pearlin, Mullan, Semple & Skaff, 1990). Pearlin`s stress process framework (Pearlin et al., 1990) focused on contextual variables in terms of primary and secondary stressors, making a distinction between stressors that are directly related to the

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caregiving role, for example, care recipient problem behaviors and sources of stress that are indirectly related like financial strain (Hilgeman, Allen, DeCoster & Burgio, 2007).

Beginning in the 1960s and 1970s, stress was considered to be a transactional phenomenon dependent on the meaning of the stimulus to the perceiver (Antonovsky, 1979; Lazarus, 1966). Lazarus pioneered the studies on emotion and stress. For example, Lazarus and his colleagues developed a measure called Ways of Coping (Folkman & Lazarus, 1980); which has since been revised (Folkman & Lazarus, 1985; Carver, Scheier & Weintraub, 1989). Together with Folkman, Lazarus developed the Transactional Model of Stress and Coping (Lazarus & Folkman's, 1984), which will be used in this study.

The Transactional Model of Stress and Coping Lazarus and Folkman's (1984) is a framework for evaluating the processes of coping with stressful events. It is an appraisal-based model and describes how people involved in caregiving cope with the stress they face. It takes into account individual appraisal of stressful events rather than the occurrence or severity of the event itself (Lazarus & Folkman's, 1984). The model is suitable for use in this study as it describes the stress response of a caregiver in providing care to a child with chronic pain. It has two key concepts; appraisal and coping (see Figure 1). Application of the model will be demonstrated throughout the discussion of the model.

This model has been used in previous studies of parenting and stress in caregivers of children with pediatric conditions (Colletti et al., 2008; Kelso, French & Fernandez, 2005; Mullins et al., 2007; Streisand et al., 2001). Lazarus (1966) noted that stress is an inevitable aspect of the human condition which consists of many variables and processes. On the other hand, Lazarus and Folkman (1984) view stress as a strain or an external demand which is higher than the person's coping resources and threatens individual's well-being.

The root cause of physical, psychological and/or emotional stress is when the individual perceives that his or her resources are inadequate to meet an environmental

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stressor (Groves et al., 2006; Hauser & Kramer, 2004). The element of stress is a consequence of person's appraisal process; the assessment of whether personal resources are sufficient to meet the demands of the environment. Stress, then is determined by person-environment fit (Lazarus & Folkman, 1984; Lazarus & Launier, 1978).

The theoretical model is built on the assumption that stress is a person-environment interaction, one that is dependent on the subjective-cognitive judgment, which arises from the interplay between the person and the environment (Zokowski et al., 2001). No event or situation in itself is inherently stressful; instead the stressor is defined by the subjective judgment of the situation that is appraised as threatening, harmful or taxing of available resources (Lazarus & Folkman, 1984). Stress, then results from the process of appraising events (as a harmful, threatening and challenging) of assessing potential responses, and of responding to these events.

Potential stressor.

Stressors are demands made by the internal or external environment that upset the balance, thus affecting physical and psychological well-being and requiring action to restore balance (Lazarus & Cohen, 1977). Stressors are potentially threatening. In this study, children's chronic pain from the diagnosis of a chronic condition such as cancer, and kidney disease is interpreted as a potential direct stressor, which threatens not only the child but also the caregivers' physical, physiological and psychosocial being.

Appraisal.

The potential stressor is mediated by the cognitive appraisals. Cognitive appraisal is an evaluating process that determines why and to what extent a particular transaction between the person and environment is stressful or else to what extent it is important to his or her general well-being (Lazarus & Folkman, 1984). Lazarus (1966) identified two forms of appraisal, namely; primary and secondary appraisal. Primary appraisals focus on the

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occurrence of an event that is significant to the caregivers' wellbeing, whereas secondary appraisal concerns coping strategies.

Primary appraisal.

According to Lazarus (1966), when an individual confronts a new or challenging environment, he or she engages in a process of primary appraisal to determine the meaning of that event. Primary appraisals include perceptions of harm which is described as the psychological loss or damage that has already taken place; threat of the anticipation of harm that may be imminent; and challenge which is the result of demands that a person feels confident in mastering. Therefore, the caregiver of a child with chronic pain derives the meaning of the stressor, how it will affect her/his wellbeing and a decision of whether the stressor is irrelevant, relevant or stressful.

Primary appraisal lays down the groundwork for the caregiver's response to providing care. The caregiver's stress response to the child's chronic pain and subsequent care then is determined by the number and type of care demands in the primary appraisal, as well as by the resources that are available to meet those demands. This can affect the caregiver's feelings of loss and grief and may influence his/her perception of the nature of the demands.

Secondary appraisal.

Secondary appraisal is the assessment of one's coping abilities as well as resources and whether they will be sufficient to meet the harm, threat and challenge of the event. The caregiver of a child with chronic pain poses questions such as; what can I do? What do I expect the outcome to be? What are the coping options? Therefore, the caregiver's subjective experience of stress is a balance between primary and secondary appraisal.

Coping.

Lazarus and Folkman (1984) define coping as a "constantly changing cognitive and behavioral effort to manage specific external and internal demands that are appraised as

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taxing or exceeding the resources of the person” (p. 141). Coping can help manage the stressful events, stress symptoms, and the meaning of events, and acts to prevent such situations (Folkman & Lazarus, 1980, 1988). Hence, secondary appraisal influences the primary appraisal by either decreasing or increasing the experience of stress, which, in turn, may influence the coping strategies adopted (Lazarus & Folkman, 1984).

In Lazarus and Folkman (1984) model, it is not the stressful situation that spells out the caregiver’s ability to adapt to challenges but rather caregiver’s coping. The model further explains that positive outcomes, such as psychological and physical wellbeing result when one has adequate buffers or coping resources to effectively handle current stressors. In contrast, negative outcomes such as depression, anxiety and physical illness, result when stressors outweigh available buffers or available coping resources.

Coping strategies.

There are two coping strategies as postulated by Lazarus and Folkman (1984) namely: problem focused and emotion focused. Problem focused strategies are defined as undertaking direct action in order to change a threatening or damaging relationship between the person and the environment. These two strategies encompass logical analysis of the situation and takes direct action to solve a problem, acquire additional resources or perform an action that will alter the source of stress (Carver, Scheier & Weintraub, 1989). Problem focused strategies may lead to adaptation if they are flexible, facilitate interpersonal communication, thereby increasing feelings of personal control, and help facilitate positive feelings (Lazarus & Folkman, 1984).

Emotion focused coping strategies refer to the actions taken to control the emotional distress produced by the person-environment relationship. It aims at reducing or managing the emotional distress that is associated with the situation (Carver, Scheier & Weintraub, 1989). Emotion focused strategies include wishful thinking, avoidance, regression and

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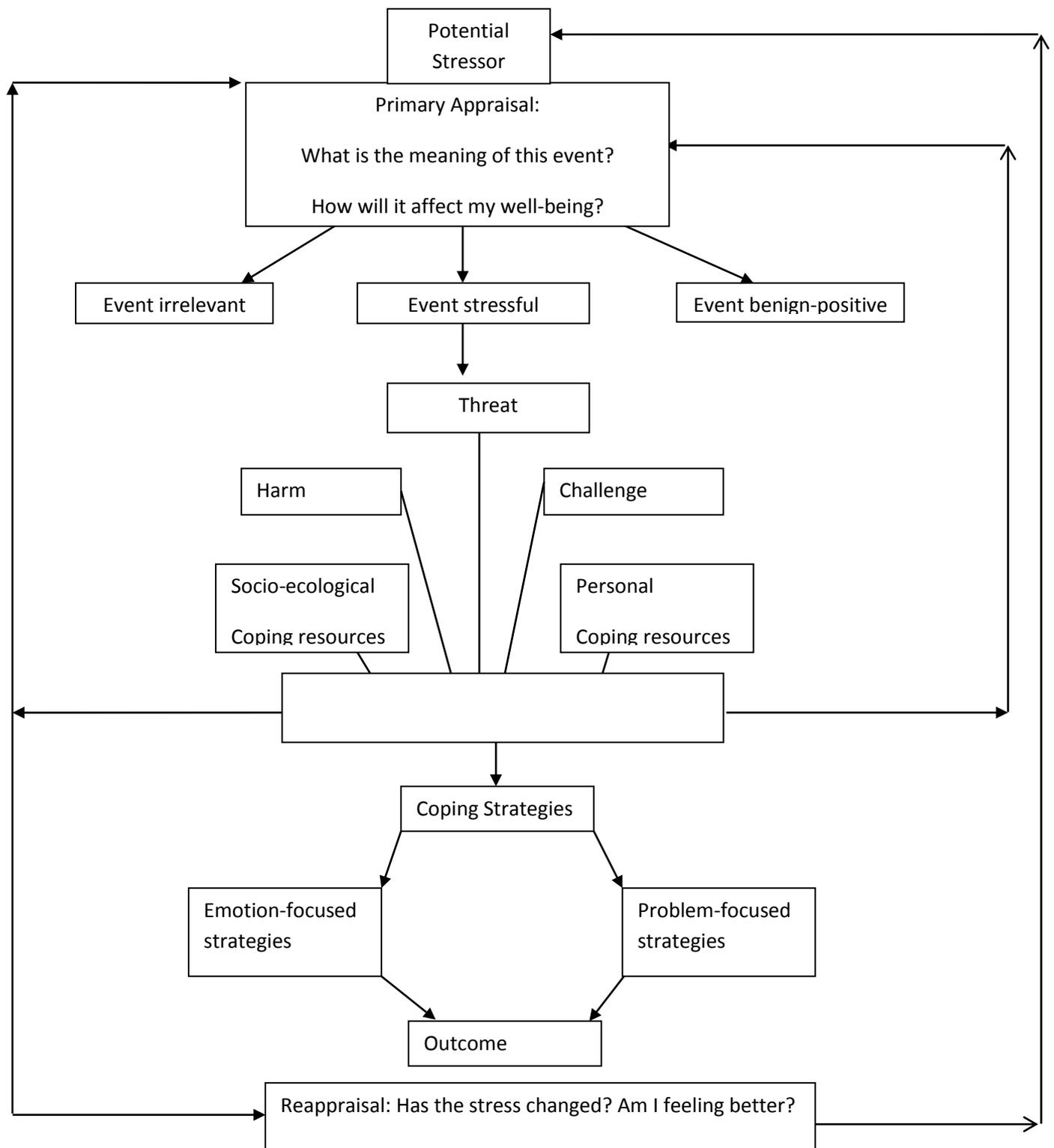
emotional discharge. Emotional strategies are maladaptive and could result in passive withdrawal avoidance behavior, feelings of self-blame, reduction of emotional ventilation, excessive dependency, and negative feelings.

Problem and emotion focused coping strategies are each capable of facilitating the other, but can also impede each other. Therefore, there is a positive relationship between recognized stress level and efforts to alleviate stress (Lazarus & Folkman, 1984).

Outcome.

Lazarus and Folkman model views outcome as a re-appraisal where the caregiver is evaluated to check improvement in the level of stress and condition of health. The significance of the outcome of a stressful event is, therefore, dependent on the caregiver's expectations. The whole model of Lazarus and Folkman model has been adapted for application in the present study. Caregivers and children suffering from chronic pain are constantly under stress. Stress is a negative emotional experience accompanied by predictable, physiological, cognitive and behavioral changes that are directed either towards altering the stressful event of caregiving or accommodating to its effects (Pearlin et al., 1990).

Figure 1: Lazarus and Folkman Process Model of Coping



Source: Beresford, B. (1994). 'Resources and strategies: how parents cope with the care of a disabled child.' *Journal of Child Psychology and Psychiatry*, 35, 171–209.

Conceptual Definitions

1. Stress is a strain or an external demand which is higher than person`s coping resources and that threatens individual`s well-being. It is a process of appraising events (as a harmful, threatening and challenging), or assessing potential responses, and of responding to these events (Lazarus, 1966; Lazarus & Folkman, 1984).
2. Coping refers to a constantly changing cognitive and behavioral effort to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984).
3. Outcome is a re-appraisal where the caregiver makes an analysis of whether the stress has changed, and also considers whether he or she is feeling better now (Lazarus & Folkman, 1984).
4. Appraisal is an evaluating process that determines why and to what extent a particular transaction between the person and environment is stressful or else to what extent it is important to his or her general well-being (Lazarus & Folkman, 1984).

Operational Definitions

1. Stress is a situation whereby a caregiver is overwhelmed with chronic pain of the child, views himself or herself as not able to take control.
2. Coping means making an effort to overcome the stress of taking care of a child with chronic pain.
3. Outcome refers to changes in the caregiver`s health and well-being as a result of giving care.
4. Appraisal refers to the extent to which a caregiver attaches meaning to the situation of a child with chronic pain. The caregiver might interpret it as a threat, harm or challenge.

Conclusion

Caregivers of children with chronic pain face challenges on resources, including time and money to effectively discharge their caregiving roles. The challenges can influence the quality of care provided for the children with chronic pain in a negative way. It is important to explore the meaning of experiences of caregivers of children with chronic pain so as to enable the health care team to support the caregivers with appropriate resources. The Transactional Model of Stress and Coping Lazarus and Folkman`s (1984), will be used to appraise events and how these impact on caregivers.

Chapter 2

Literature Review

There is a need to understand the nature of experiences of caregivers of children with chronic pain. This chapter presents a comprehensive review of caregivers' experiences of children with chronic pain. The perceived stressors and their impact on the physical, psychological, and functional health of caregivers are discussed.

Caregiver of Children with Chronic Pain

Caregivers continuously look after people with chronic conditions (National Center on Elder Abuse (NCEA, 2010). This brings in the concepts of roles and responsibilities attached to caregivers of children with chronic pain, which ought to be done with love and commitment (Pearlin et al., 1990).

The two forms of caregivers are formal and informal. Formal caregivers are those who are employed to provide care to the recipients. These may include health professionals such as nursing staff, or untrained caregivers (Pearlin et al., 1990). In contrast, informal caregivers are family members, friends, or neighbors who provide unpaid care and support for a loved one who is frail, has a long term illness or disability. Family members who can be caregivers may include parents, children, or siblings, other relatives.

For the purpose of this study, informal caregivers are defined as caregivers who provide unpaid care to recipients in need of care (Lazarus, 1984), and children with chronic pain under this study are the recipient of care. Therefore, individuals in the home setting caring for a child with chronic pain fulfill the role of a caregiver. The study will explore caregiver's roles that include both the affective and practical components of caregiving.

A lot of time is most significantly invested in caregiving which is provided mainly in home settings. The roles and responsibilities of caregivers depend on the type of illness or disability and associated chronic pain of individuals (Moskowitz et al., 2007). Caregivers of

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children with chronic pain provide services like bathing, feeding, giving medications, and taking children for medical checkups. However, caregivers may experience great strain, stress and burden which results in negative physical and psychological health outcomes (Bernstein & Cozen, 2007).

Need for Caregiving to Children with Chronic Pain

Caring is an integral part of any close relationship (Pearlin et al., 1990), and as the chronic pain status increase, family members and friends often assume caregiving role (Crespo, Lopez & Zarit, 2005). Chronic pain can develop as a result of motor vehicle accidents, other personal injuries e.g., sports injuries or home accidents, surgeries, medical procedures, and chronic medical conditions, e.g., leukemia, cancers, meningitis (Winterowd, Beck & Gruener, 2003). Similarly, most childhood terminal and chronic illnesses like chronic headache, recurrent abdominal pain, fibromyalgia, sickle cell disease, epilepsy and juvenile idiopathic arthritis manifest with chronic pain (Eccleston et al., 2012).

Inflammatory joint disorders, e.g., juvenile rheumatoid arthritis or ankylosing spondylitis can cause chronic back pain in children and adolescents, and sacroiliac joint tenderness may be present (Bernstein & Cozen, 2007). Children with inflammatory joint disorders present with severe pain, distressed mood, and disability which tend to be progressive (Eccleston et al., 2012; Kashikar-Zuck et al., 2011). Therefore, chronic pain can lead to reduced mobility and consequently loss of strength, compromised immune system, and can interfere with a child's ability to eat, concentrate, sleep, or interact with others.

Sickle cell anemia pain is characterized by unpredictable recurrent acute and vaso-occlusive crises that can result in intense pain experiences that last for hours to days (van den Tweel et al., 2008). It is often the feature that brings the affected child to seek medical attention. However, most episodes are managed at home without contact with health care workers. Therefore, repeated chronic pain can have a major impact on the child's normal

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activities, such as school attendance, school progress, and sleep quality and quantity (van den Tweel et al., 2008).

Caregivers Assessment and Management of Chronic Pain in Children

Childhood chronic pain represents a pediatric developmental health issue. Children who suffer from chronic pain have a right to have their pain properly assessed and managed well (Haraldstad et al., 2011). Therefore, caregivers have a critical role to play in the development of pain assessment and management skills.

Assessment and management of chronic pain in children includes knowledge of the physical, psychological and physiological stages of development of the child and an understanding of how a child may react to the stress of pain. There are important ways that caregivers can influence a child's pain experience; this includes the presence of caregivers during procedures and ability to assess child's pain (Kuttner, 2004).

Winterowd, Beck and Gruener (2003) indicate that understanding the subjective nature of children's pain will promote empathy and facilitate treatment planning. Kuttner (2004) articulated the valuable role of parents as caregivers to assess and interpret children's pain and coaching behaviors that promote coping for the child. A child with chronic pain can report his or her pain through various techniques. Self-report technique is based on the ability of the child to communicate his or her pain experience. Children from 6-13 years are able to describe their feelings and the images that they have of their pain (Azize, Humphreys & Cattani, 2011).

Children's behavior may and may not reflect pain self-reports. Therefore, caregivers should conduct pain behavioral assessment that can positively or negatively reinforce children's pain behaviors. Haraldstad et al. (2011) interviewed parents of children with chronic pain aged 8-18 years. Positive reinforcement occurs in the context of responsive caregivers who respond in a protective manner to a child with chronic pain. The positive

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reinforcers which physically and verbally comfort the child include hugs, and kisses, and coming to the child's side. On the other hand, negative reinforcers cause the child to avoid activities that are seen as unpleasant. Haraldstad et al. (2011) results are relevant in this proposed study as the sample includes the same age group of children 6-13 years under study.

Through interaction with the child with chronic pain, the caregiver needs to understand the verbal and non-verbal pain cues. Verbally, a child can request or demand something from the caregiver. In contrast, non-verbal cues observed in children include isolation, crying, aggression, groaning, moaning or protective posture. Examples of protective posture are holding a limp so it does not move to cause more pain, tensing, limping, grimacing, or pulling on an ear (Dahlquist, 1999).

Caregivers at times have to take decisions that disadvantage the child in pain. This is so because children can develop adaptive coping behaviors. For example, a child who remains in good spirits despite pain may not receive his/her pain medications. In such cases, the child quickly learns to maintain pain behaviors to prevent the medication from being taken away (Gorodzinsky, Bernacki, Davies, Drendel & Weisman, 2012). The same authors concluded that parents commonly used certain techniques that are based on gender and age of the child. In support, Haraldstad et al. (2011) found that some parents overestimated pain in boys and girls of the youngest age group, and underestimated the pain of older girls.

Caregivers should pay attention to signs that indicate pain in children. These may include; facial expressions such as grimacing; breathing and sighing heavily; unusual body movements, such as limping; behavioral changes such as not wanting to eat or sleep; emotional changes such as crying or irritability. Assessment of the emotional and spiritual needs of the child facilitates advance care planning and appropriate referrals to health care specialists. For example, in a situation of a life-threatening condition, children may grief loss

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of function, interaction, and participation in developmentally appropriate activities of daily living such as play and school (Himmelstein, Hilden, Boldtand & Weissman, 2004).

Caregivers use different techniques of managing pain at home. Gorodzinsky et al., (2012) found that parents reported three most common techniques; providing comfort to their child, applying ice to the site where pain is located, and providing the child with a massage. The same study by Gorodzinsky et al., reported that parents used more non-pharmacological techniques for children between the ages of 6 and 11 years than for children between 2 and 5 years of age and adolescents 12 to 17 years of age.

Caregivers Responsibilities

Caregivers spend a substantial amount of time interacting with their children with chronic pain using a wide range of activities of providing care. More than half of family caregivers provide 8 hours of care or more every week, and one in five provides more than 40 hours per week (National Alliance for Caregiving (AARP), 2004). Mothers felt caring for a child with chronic kidney disease (CKD) on dialysis machine consumes their time, thoughts and energy causing fatigue (Tong, Lowe, Sainsbury & Craig, 2010).

Due to inadequate knowledge and skill, caregivers may be unfamiliar with the type of care to be provided to the child, the amount of care needed, and this may unintentionally harm the loved one (Reinhard, Given, Petlick & Bemis, 2008). Caregivers may find themselves stressed up by provision of activities of daily living (ADLs).

Personal care includes assistance in tasks as bathing, dressing, walking, eating, assisting the child to get in and out of a bed or chair, grooming, taking medications, cutting nails, and toileting. Household activities include: (a) housework, bed making, laundry, preparing meals, cleaning, washing floors, and vacuuming; and (b) household maintenance: washing windows, minor repairs, and maintaining the yard.

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Shopping and transportation include shopping for household items and taking the child for check-ups, or emergencies. Emotional Support involves assistance in maintaining social interaction, providing opportunities for socialization.

Monitoring care encompasses ensuring the child's needs are met and quality of services provided. In pursuit of monitoring the care rendered to children with cancer, Björk (2008) states that together with health personnel, the parents interacted with children and were even involved in administration of medical procedures, some of which the children perceived as painful such that they even begged the parents to take them away from the procedure.

Parents of children with CKD are often required to deliver home-based interventions including dialysis and enteral feeding. They continuously monitor their child's health, advocate for appropriate health care, prepare for episodes of infection and other life threatening complications and attend frequent hospital appointments (Nicholas, 1999). Similarly, Tong et al. (2010) studied children with CKD, and found that in the hospital, parents felt they became advocates for their children; battling to meet seemingly endless clinical appointments including pathology tests, x-rays; biopsies and waiting for prescriptions and collecting equipment from the appliance departments.

Caregiver's demands and role strains

Primary appraisal of events threatens the physical, psychological, emotional and functional health of caregivers (Etters & Harrison, 2008). Caregivers who attempt to balance caregiving demands with other activities, such as work, family, and leisure, may find it difficult to focus on the positive aspects of caregiving and often experience more negative reactions, such as an increased sense of burden (Mawani et al., 2013). In contrast, when a child is ill, coping, and strategies dealing with threats such as chronic pain, can be useful for both the caregiver and the child and it helps the caregiver and family to maintain and restore

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a balance between demands and resources as well as to lessen the intensity of perceived stressors (Pearlin et al., 1990). This was later supported by a quantitative study by Gallagher-Thompson, Coon, Rivera, Powers and Zeiss (1998), who reported that 75% of caregivers felt that caregiving, makes them feel useful; possible positive feelings include self-worth and confidence.

Caregiver and stressors

Stressors can threaten or produce a change in the family's roles, functions and belief system. Pakenham, Chiu, Bursnall and Cannon (2007) found that higher stress appraisals were related to higher distress and lower life satisfaction. The stressors can cause more mood problems and poor pain coping strategies to the caregiver. The stressors can be the children's roles, activities and relationships with others such as siblings, friends, school mates and other relatives. Mawani et al. (2013) found that children less than 16 years with juvenile idiopathic arthritis (JIA) reported a limitation of their activities because of chronic pain, stiffness, and fatigue, which have an impact on their autonomy and quality of life. The findings are relevant for this study to be conducted in children 6-13 years even though the method of study is cross-sectional.

Caregiver's coping

Coping is a concept that has been described in many studies and has different meanings. Lazarus and Launier (1978) viewed coping as a series of transactions between a person who has a set of resources, values and commitments and a particular environment with its own resources, demands and constraints. On the other hand, Pearlin and Schooler (1978) described coping as the response to the external strains on life that can prevent, avoid, or control emotional distress. In this study, Lazarus and Folkman (1984) description of coping will be used. According to the authors, actions and emotions work together and

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coping will continuously mitigate the symptoms of stress and manages the stressful situations.

Coping strategies of dealing with threats such as chronic pain can help the family to maintain and restore a balance between demands and resources as well as to lessen the intensity of perceived stressors (McCubbin & McCubbin, 1993). Sometimes thoughts about life gradually change and new values can be gained. On the other hand, the same authors state that stress may result in erosion of caregivers coping responses.

The experiences of a caregiver regarding stress has been found to be related to how the individual appraises (give meaning) to the stressful situation. Lazarus and Folkman (1984) postulates that appraisals are unique to individuals, hence may appraise their meaning quite differently. For example, some caregivers may perceive care demands as burdensome, while others perceive demands as ordinary expectations. Caregivers, who report negative effects in their role of caregiving, are likely to report reduced wellbeing. In contrast, caregivers who give positive meaning to caregiving with the availability of social support and greater social support networks are more likely to experience greater wellbeing (Pakenham, Chiu, Bursnall & Cannon, 2007).

Parents described a number of strategies that they used for coping with caring for a child with asthma, such as accepting it (resigned acceptance), social support and, less often, positive reappraisal and religion. These studies support the assumption in the revised Pender's model (1996) that individual's perceived benefits of behavior, perceived barriers, perceived self-efficacy, emotions related to a behavior influence an individuals' commitment to a plan of action (Pender, 1996).

Children with chronic pain should be encouraged to stay involved in activities according to their pain tolerance level to participate in life as a way of coping. Although many children with chronic pain appear depressed, anxious, or angry, there are some children

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who develop a sick role as a way of coping to receive attention, sympathy, dependency, and exemption from responsibilities at school or home (Dahlquist, 1999).

Delivering care to a child who is persistently complaining or displaying pain behaviors can be very stressful to the caregivers. The caregivers may become less invested in their children's care if they experience that they are being used or taken advantage of (Winterowd, Beck & Gruener, 2003), and the child would be at risk of poor assessment and management of their chronic pain. The emotional challenges experienced by the caregivers can translate into poor coping and, as a result, they may have a negative impact on the quality of care provided to the child (Brehaut et. al, 2009).

Caregivers stressors, e.g., care recipient problem behaviors can result in increased use of avoidance coping and restriction of social activities, along with a reduced sense of personal mastery and self-efficacy for using problem-focused coping. Pender's Health Promotion model (1996) contends that situational factors, such as caregiver burden, may affect participation in health promotion activities. Therefore, information-seeking is described as one of many problem-solving strategies (Pender, 1966). Some parents became more assertive and self-confident as they sought information. Crying and grieving also helped parents to release emotional stress.

Impact on Caregiver Health

Caregivers are hidden patients themselves, with serious adverse physical and mental health consequences. Caregiver's roles are physically and emotionally demanding and ultimately have reduced attention to their own health and health care (Reinhard et al., 2008). In addition, caregivers experience significant financial stressors in association with their caregiving role. The quality of care received by children may be affected by the caregivers' well-being. This is supported by Eppers and Harrison (2008) who reported that primary

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appraisal of an event is a burden to caregivers as it threatens the physical, psychological, emotional and functional health of caregivers.

Studies focusing on psychological health effects in caregivers show increases in psychological symptoms, such as depression, anxiety and emotional distress (Schulz & Beach, 1999). Nevertheless, caregiving can be a rewarding and positive experience. For example, Mawani et al. (2013) found that caregiving for children with juvenile idiopathic arthritis (JIA) can also enhance self-esteem in parents who feel satisfied and gratified by helping their children.

Sisk (2000) indicate that the feelings involved in caregiving, such as fear, pain, loss, and guilt may interfere with one's holistic and spiritual well-being as well as one's abilities to keep in contact with medical help and to eat a balanced diet. No wonder the same author recommended that the studies demonstrating the effects of interventions designed to deal with the feelings involved with caregiving or to decrease the losses experienced by caregivers are warranted.

Physical Consequences on Caregivers' Health

Caregivers are critical to the well-being of children, and their own well-being is inextricably linked to that of their children. Caregiving may affect caregiver's various body systems which often lead to physical conditions that may be disabling. Vitaliano, Schulz, Kiecolt-Glaser and Grant (1997) reported that caregivers experience poorer immune system functioning, poorer response to vaccines, and greater incidences of respiratory tract infections. Caregivers observing a child receiving a painful stimulus, like being given an injection may also experience a degree of pain response, for example, increased heart rate, blood pressure (Kennedy, Luhmann & Zempsky, 2008).

Psychological Consequences on Caregivers Health

Caregiving roles impose significant problems and burden on caregivers. Being a parent of a child with a chronic illness or disability with associated chronic pain may lead to psychological distress (Zelikovsky, Schast & Jean-Francois, 2007). In their review of the literature between 1997 and 2007 on parental stress reactions following the diagnosis of childhood cancer, Vrijmoet-Wiersma (2008) found that feelings of uncertainty, anxiety, depressive symptoms are most prevalent in parents shortly after confronted with the diagnosis of childhood cancer. They also reported that the severity of stress lessened overtime in the majority of parents, but have been found to persist in a substantial proportion of the parents even many years after post treatment.

Some caregivers may display contradictory psychological reactions in caring for a child with chronic pain. As such, a child's pain may become intimately experienced as the caregiver's pain, becoming more worried and protective to their child. In a study on children who completed treatment for cancer, the family as caregivers was relieved that treatment was over, but also concerned about how they would manage the new situation should anything happen to their child (Ortiz & de Lima, 2007).

Conclusion

Chronic pain can have a major impact on the child's activities of daily living, such as school attendance, playing, eating and sleeping habits. Caregivers of children with chronic pain provide services like bathing, feeding, giving medications, and taking children for medical checkups. The experience of caregiving can be positive and growth-enhancing. On the other hand, some caregivers may experience great stress which results in negative physical and psychological health outcomes. The reviewed literature revealed that caregivers use different coping strategies to manage children with chronic pain.

Chapter Three

Methodology

Introduction

This chapter presents a discussion of the methodological processes including the research design, population, sampling, data collection methods, data analysis, and ethical considerations.

Study Design

A descriptive phenomenological qualitative design will be used to gather data on experiences of caregivers of children with chronic pain.

Population

The population includes all elements that meet certain criteria for inclusion in a study (Polit & Beck, 2012). For the purpose of this study, the accessible population will consist of family members who directly care for the child with chronic pain in Scottish Livingstone Hospital (SLH) in Molepolole.

Setting

The study will be conducted in SLH paediatric ward in Molepolole. SLH is the only district hospital in Kweneng district council. It has a paediatric ward which admits children (6-13 years) with chronic conditions like cancer, arthritis which elicit chronic pain. Prospective caregivers can be easily accessed in the ward during visits or admissions of children to the paediatric ward.

Sampling

A non-probability purposive sampling is predominantly used in qualitative research; hence it will be used to obtain study participants. The participants will be purposively selected in SLH paediatric ward, as they are the ones with rich in-depth information that will illuminate their lived experiences of caregiving to children with chronic pain. Snowball

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sampling will also be used to access additional participants. The assumption is that friends, neighbors and relatives share common life experiences. Therefore, snowballing will be achieved by asking one participant to recommend other caregivers whose children have similar problem of chronic pain.

Sample Size

Sample size will be guided by data saturation where interviews will continue to the point at which no new information will be derived and redundancy is achieved. The adequacy of the sample size will be evaluated by the completeness and quality of the information provided by the participants who have experiences of caring for children with chronic pain. Phenomenological studies tend to rely on very small sample-typically 10 or fewer participants (Polit & Beck, 2012). The researcher aims at a sample of 10 which will allow for large amount of data acquired from each participant to be analysed without much challenge.

Inclusion criteria

The sample will consist of participants who: a) provide care-giving services such as bathing, feeding or giving treatment to the child with chronic pain, b) are primary caregivers, for example, parents or relatives, c) must have cared for the child with chronic pain for three months or longer, d) are over the age of 21 years, e) are non-paid for care-giving services.

Exclusion Criteria

All caregivers who: a) have cognitive challenges b) have not provided care to a child with chronic pain for more than 3 months will be excluded.

Recruitment

Recruiting participants for a study involves identification of eligible candidates and persuading them to participate. Posters in Setswana and English will be placed in all the notice boards in SLH for prospective participants who cared or are caring for the children with chronic pain (**Appendix F**). Assistance will be solicited from the nurses in paediatric

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ward as they are gatekeepers in identifying the participants. This is because nurses take care of the children 24 hours when they are hospitalized.

The researcher is aware of factors that may facilitate or hinder recruitment of participants by gatekeepers; these include time, commitment, responsibilities, gatekeeper and participant relationship. The researcher will hasten the recruitment process by also participating in recruiting prospective participants face to face in paediatric ward. In case of prospective participants with low literacy level, the researcher will read the poster to them and clarify further.

The gatekeepers will be asked to record names and contact details of the prospective participants. This will be used to make appointments on convenient place and time for the interviews. To eliminate possible bias, the gatekeepers will be advised to recommend all potential participants to the study. The objectives and implementation of the study will be explained to the gatekeepers. Informed consent and assent will be obtained during the interview period.

Ethical Considerations

Permission to conduct the study among caregivers of children with chronic pain will be sought from various Institutional Review Boards (IRBs): Office of Research Development (ORD)-University of Botswana (**Appendix B**), Health Research Unit-Ministry of Health (**Appendix C**), and Ethics Committee-Scottish Livingstone Hospital (**Appendix D**).

Informed consent and assent will be obtained from caregivers and children respectively. However, the participants and the children will be informed that they have the right to participate in the study freely and to withdraw without any explanation or fear of victimization (**Appendices G and H**). The participants will be informed that they are selected as they directly give care to the child with chronic pain. Children will also be informed that the study will be carried on caregivers who look after their needs as they are sick. The

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interview guide, recruitment poster, informed consent and assent forms will be both in English and Setswana languages. Participants name will be substituted with codes to assure anonymity. Data collected, transcribed audio interviews and field notes will be kept in a locked cabinet. The dedicated laptop used for the project will be password protected.

Data Collection

The researcher will collect data from the caregiver using the demographic information forms for the caregiver and the child (**Appendix A**), and semi structured interview tool (**Appendix I**). Field notes which will be captured and detailed notes written immediately after the interviews.

Interview process

The purpose of the study will be explained and informed consent and assent will be obtained. Participants will be assured of confidentiality as explicated in consent form (**Appendix G**). In addition, the researcher will ask for permission to record the interviews.

Data will be collected through face-to-face semi-structured interviews. This method promotes a conversation between the participant and the researcher, hence allowing immediate clarification and elaboration of participant's experiences (Chan et al, 2013). The researcher will put aside own knowledge and experience which help to minimize the influence of the researcher throughout the research process. The researcher will employ reflective journaling to record personal reflections as a key tool to bracketing.

The length of the interviews will not be constrained as the participant's responses will guide the direction and length of the interview (Englander, 2012). However, interviews are estimated to last 45 to 90 minutes. Each participant will be assigned a code, for example, "Participant 001", for the first interviewee; "Participant 002," for the second interviewee and the same trend will be followed throughout the data collection process. The interviews will be

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audio taped with permission from the participants to allow the researcher to capture the tone of voices, pauses, and silences, and to some degree, the emotion displayed of the interviews.

The interviews will be based on 10 open ended questions developed by the researcher for the purpose of this study (**Appendix I**). The questions will be structured around caregiver's knowledge on caring for a child with chronic pain, and designed to facilitate expression of personal narratives and experiences. The sequencing of the questions will be the same for every participant.

The main question for each participant will be presented like, "In as much detail as possible, tell me what it is like for you to care for the child with chronic pain?" This general question is open-ended and intends to allow participants a wide range of responses in which they can verbally describe the experiences without constraint.

The researcher will implore probing questions for clarification, and to set direction, for example, when, who, and where. Field notes captured will describe the behaviour or facial expression, gestures and interviewee's reactions or other factors like environment. At the end of the interviews, a leading question will be posed like: "Is there anything more about your experience that you feel is important to mention?" Data analysis will be done simultaneously with data collection. A debriefing session will be done at the conclusions of the interviews.

Data Analysis Plan

The researcher will use the following Colaizzi's (1978) seven procedural stages to elicit emerging themes that will describe the experiences of caregivers of children with chronic pain.

Stage 1: All audio-taped interviews which include key words, phrases, statements and field notes will be transcribed verbatim as soon as possible after each interview to ensure an accurate record of the participants' words.

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Stage 2: The transcripts will be read and re-read to extract words and sentences relating to the phenomenon of care-giving of a child with chronic pain. A highlighter pen will be used to identify significant words and phrases. These segments of text will then be given the descriptive label of 'significant statement'.

Stage 3: The highlighted significant statements will then be physically cut and sorted into groups of similar ideas that will be pasted together to begin to formulate meanings.

Stage 4: The formulated meanings will then be clustered into common themes and extraction of essential structure of the phenomenon will be done. Therefore, a number of emerging themes will be reported.

Stage 5: Using significant insight, immersion in the data will reveal themes that comprise of formulated meanings relating to appropriate subcategory of experiences.

Stage 6: An exhaustive description of the results will be written and condensed into a statement of fundamental structure made up of different emerged themes of caregivers' experiences of caring for their children with chronic pain. Throughout data analysis, the researcher will continually refer back to the field's notes to ensure the participant's descriptions are captured. The researcher will also refer back to the transcripts to find words that the caregivers had used during their descriptions which would best fit the themes.

Stage 7: The researcher will validate the descriptive results by returning back to two participants to confirm if this analysis describes their experiences.

Pilot Study

The researcher proposes to carry out a pilot study on two participants in SLH, paediatric ward, the same setting for the main study. This will assist the researcher to appreciate the strengths and challenges, and effectively intervene before the main study is conducted. The caregivers who will be involved in pilot study will not be included in the main study. Including caregivers who participate in the pilot study can introduce bias in the

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study findings, because the caregivers would have prior knowledge of the type of interview questions.

The researcher is aware that in descriptive phenomenological studies, each participant describes his/her experiences differently; therefore the researcher will only attempt to pilot the sampling method, questions and functionality of the audiotape machine. Moreover, the researcher seeks to build more confidence in the interviewing skills and gaining trust of participants.

Rigour

Trustworthiness of data collected from direct observations and interviews in this study will be ensured by applying Lincoln and Guba's (1985) criteria which include: credibility, dependability, confirmability and transferability.

Credibility.

This is where the participants identify the research findings as their own information and experiences. The study will depict researcher's development of themes and essences that accurately reflect the experiences of caregivers of children with chronic pain. The researcher will conduct debriefing with participants. Credibility will also be ensured by member checking of two participants so as to identify with their transcripts and to have an opportunity to provide additional insight and information.

Dependability.

Dependability is an assurance for study findings to be believed and have meaning to the readers (Lincoln & Guba, 1985). The researcher densely described the methodology, and will be consistent in the research process and rich documentation of the study's processes. Data will be organized in themes (Polit & Beck, 2012). Any other material relevant to the study will be made available and accessible to the supervisor and any other researcher, for the purpose of conducting an audit trail.

Confirmability.

Confirmability is the objectivity or neutrality which shows the degree to which study's results can be substantiated by others (Lincoln & Guba, 1985). It assists in the control of researcher bias. The researcher will ensure that data represent participant's information, and interpretations of data are not invented by the researcher. An audit trail consisting of documentation of procedures like data collection, field notes, periodic debriefing sessions between the researcher and the research advisor, reflexive journaling and analysis will be kept.

Transferability.

Lincoln and Guba (1985) refer to transferability as the evidence supporting the representation of findings to other contexts across different participants, groups, or situations. Therefore, the setting and participants have been described thoroughly. Moreover, a review of literature has been conducted wherein similar findings of other studies were reported.

Limitations

This is a descriptive phenomenological study that implores a very small sample of ten participants; therefore the findings will be representative of SLH, pediatric ward only. The findings will benefit the staff in implementing interventions that address caregivers who take care of children (6-13years) with chronic pain. This may facilitate appropriate management of the children with chronic pain.

Dissemination of findings

Findings will be disseminated in the form of a research report. The expected audiences are health care service providers, and non-governmental organizations supporting caregivers of children with chronic pain.

Budget

Appendix J indicates expected resources that will be needed to carry out this proposed study.

Conclusion

A phenomenological approach is well suited for examining the experiences of caregivers. More specifically, the use of descriptive phenomenology will allow the researcher to directly explore and analyse phenomenon to arrive at a description of the lived experiences of caregivers of children with chronic pain. A rigorous process of inquiry will result in sound empirical findings that will guide health care workers in support of caregivers of children with chronic pain.

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APPENDICES

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

APPENDIX A: Demographic Data Sheet (Caregivers)**PLEASE TICK AS APPROPRIATE IN THE OPTIONS GIVEN BELOW****Name:** _____**Gender:** F _____ M _____**Phone:** _____**Date of Birth:** _____**Are you employed?** _____ If yes: **Full time** _____ **Part Time** _____**Are you the Primary Caregiver?** _____**Duration of Caregiving:**

3-6 months _____

1-2 years _____

3-4 years _____

5-6 years _____

Marital Status:

Single _____

Married _____

Divorced _____

Widowed _____

Education:

None _____

Primary _____

Secondary _____

Tertiary _____

Average Income per month:

Less than P1000 _____

P1001 to P5000 _____

P5001 to P10000 _____

P10001 to P20000 _____

More than P20001 _____

Unemployed _____

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

APPENDIX A: Demographic Data Sheet (Child)

To Be Completed By Caregiver

Childs Name_____

Age of Child_____

Date of birth_____

Diagnosis of the child_____

Date of diagnosis_____

APPENDIX B: Semi-Structured Interview Guideline-Caregivers (English)

1. In as much detail as possible, tell me what it is like to care for the child with chronic pain
2. Briefly explain the type of care you provide on daily basis?
3. How effective is the care provided to the child with chronic pain?
4. What are the potential stressors in caring for the child with chronic pain?
5. What are the events that lead to the potential stressors?
6. Please explain the meaning of the stressors-whether irrelevant, relevant or stressful?
7. Describe the availability and sufficiency of resources like finances, transport, or any support to meet the demands of caregiving?
8. What coping strategies have been helpful in caring for the child with chronic pain?
9. What are the outcomes (positive and negative) from the experience of caregiving?
10. Do you have anything else to share?

APPENDIX B: Semi-Structured Interview Guideline-Caregivers (Setswana)**POTSOLOSO YA BATLHOKOMEDI BA NGWANA OO TSHELANG KA BOTLHOKO MO MMELENG**

1. Tlhalosa ka bophara jo bo kgonagalang ka fa o e tseng tlhoko ka teng ka tlhokomela ya ngwana wa gago yo o tshelang ka ditlhabi mo mmeleng
2. Ka boripana, tlhalosa mefuta ya tlhokomelo e o fang ngwana tsatsi le letsatsi
3. Tlhokomelo e e fiwa ngwana e mosola go le kae?
4. Ke a fe matshwenyego a o kopanang le o ne mo tlhokomelong ya ngwana o o tshelang ka botlhoko mo mmeleng?
5. Ke ditiragalo dife tse di felelang di tsisa matshwenyego?
6. A o ka tlhalosa gore matshwenyego a, a rayang mo go wena-gore a ke a a lebaneng, kana nnyaa?
7. Tlhalosa ka kakaretso ditlamelo tsotlhe tse o di amogelang gongwe le gonwe, le boleng jwa teng jo bo itebagantseng le letlhoko la tlhokomelo ya ngwana
8. Ke bo fe boikokotlelo jo bo go kgontshang go tlhokomela jo bo nnang le maduo?
9. Ao ka akgela ka maduo a a molemo le a a seng molemo, a o a fitlheletseng ka tlhokomelo ya ngwana?
10. Ko bofelong, a go na le sengwe se o eletsang go se kgaogana le nna?

APPENDIX C: Permission to Conduct a Study (University Of Botswana)

University of Botswana
School of Nursing
P/Bag 0012
Gaborone
31.05.2016

Director
Office of Research Development (ORD)
University of Botswana
School of Nursing
P/Bag 0012
Gaborone

Dear Sir/ Madam

Permission to Conduct a Study: Experiences of Caregivers of Children (6-13 years) with Chronic Pain in Scottish Livingstone Hospital in Molepolole

This letter serves to seek permission to undertake a study in Scottish Livingstone Hospital in Molepolole. I am a third year Master of Nursing Science (MNSc) student at the University of Botswana, School of Nursing. I am required to undertake a study in partial fulfilment of the MNSc programme. The purpose of this study is to understand the experiences of caregivers of children (6-13years) with chronic pain. I expect that this study will inform practice and policy making.

I have enclosed my research proposal.

Yours faithfully,

Gomolemo Oodira.

APPENDIX D: Permission to Conduct a Study (Ministry Of Health)

University of Botswana
School of Nursing
P/Bag 0012
Gaborone
31.05.2016

The Research Coordinator
Human Resource Development Council (HRDC)
Ministry of Health
P/Bag 0038
Gaborone

Dear Sir/Madam

Permission to Conduct a Study: Experiences of Caregivers of Children (6-13 years) with Chronic Pain in Scottish Livingstone Hospital in Molepolole

This letter serves to seek permission to conduct a study in Scottish Livingstone Hospital in Molepolole. I am a third year Master of Nursing Science (MNSc) student at the University of Botswana, School of Nursing. I am required to undertake a study in partial fulfilment of the MNSc programme. The purpose of this study is to understand the experiences of caregivers of children (6-13years) with chronic pain. I expect that this study will inform practice and policy making.

I have enclosed my research proposal.

Yours faithfully,

Gomolemo Oodira.

APPENDIX E: Permission to Conduct a Study (Scottish Livingstone Hospital)

School of Nursing
P/Bag 0012
Gaborone
31.05.2016

Chairperson
Ethics Committee
Scottish Livingstone Hospital
P O Box 984
Molepolole

Dear Sir/ Madam

Permission to Conduct a Study: Experiences of Caregivers of Children (6-13 years) with Chronic Pain in Scottish Livingstone Hospital in Molepolole

This letter serves to seek permission to undertake a study in Scottish Livingstone Hospital in Molepolole. I am a third year Master of Nursing Science (MNSc) student at the University of Botswana, School of Nursing. I am required to undertake a study in partial fulfilment of the MNSc programme. The purpose of this study is to understand the experiences of caregivers of children (6-13years) with chronic pain. I expect that this study will inform practice and policy making.

I have enclosed my research proposal.

Yours faithfully,

Gomolemo Oodira.

APPENDIX F: Permission to Conduct a Pilot Study (Scottish Livingstone Hospital)

University of Botswana
School of Nursing
P/Bag 0012
Gaborone

31.05.2016

Chairperson
Ethics Committee
Scottish Livingstone Hospital
P O Box 984
Molepolole

Dear Sir/ Madam

PERMISSION TO CARRY OUT A PILOT STUDY

This letter serves to seek permission to undertake a pilot study in Scottish Livingstone Hospital in Molepolole. This is in preparation for the main study that I am required to undertake in partial fulfilment of the Master of Nursing Science (MNSc) programme. The purpose of the study is to understand the experiences of caregivers of children (6-13years) with chronic pain.

I am a third year MNSc student at the University of Botswana, School of Nursing.

I have enclosed my research proposal.

Yours faithfully,

Gomolemo Oodira.

APPENDIX G: Study Recruitment Poster (English)

A researcher from the University Of Botswana, School of Nursing is conducting a study on experiences of caregivers of children (6-13 years) with chronic pain. It will be appreciated if you could assist by participating in the study if you are one of those described below:

- *Are you a caregiver for a child with chronic pain?*
- *Have you lived with the child with chronic pain for more than 3 months?*
- *If you would like to participate in my study, your involvement will consist of an interview at a location convenient for you to talk about your experience.*

To discuss how to participate, please contact me at:

- gomolemooodira@yahoo.com
- 72150259
- 3902269

APPENDIX G: Study Recruitment Poster (Setswana)**IPAPATSO YA GO NGOKA BATSENELELA DIPATLISISO**

Mmatlisisi go tswa ko sekolong se setona sa Mmadikolo (University of Botswana) mo Gaborone, mo lephateng la booki o ikaelela go batlisisa ka maitemogelo a batlhokomedi ba bana ba ba tshelang ka botlhoko mo mmeleng, ba ba dingwaga di magareng ga borataro go ya go lesome le boraro (6-13 years). Go ka lebogesega fa o ka nna mo tsaya karolo fa o le mongwe wa batho ba ba nankotsweng baba latelang:

- *A o motlhokomedi wa ngwana o o tshelang ka botlhoko mo mmeleng?*
- *A o tshetse le ngwana yo go feta dikgwedi tse tharo?*
- *Ga o eletsa go tsaya karolo mo patlisisong e, o tlaa botsolotswa kwa lefelong le nako e e go siametseng.*

Go buisana ka go tsaya karolo, itshwareganye le nna kwa di nomoreng tse di latelang:

72150259, 3902269

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

APPENDIX H: Informed Consent-Participant Information Sheet (English)

You are being asked to take part in a study. This form provides you with information about the study. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary.

Title of Research Study: Experiences of Caregivers of Children (6-13years) with Chronic Pain

Principal Researcher and Telephone Number: Gomolemo Oodira (+26772150259)

Source of Funding or Other Support: Self

Aim of this research study: To seek an in depth understanding of experiences of caregivers of children (6-13 years) with chronic pain.

You will fill out a personal data questionnaire. The initial interview is expected to last between 45-60 minutes, describing your experiences as a caregiver. Further interview will be determined after analysis of the data to verify your data given.

The interviews will be scheduled at a time and place of your convenience with less distraction, like your home, hospital premises or anywhere you are comfortable with. The interviews will be audio-taped. You might experience emotional distress and/or fatigue as you describe your experiences. No gifts or money will be provided. You are free to withdraw your consent without any penalty. No identifying information will be used. Access to the data collected will be restricted to the researcher and supervisor.

All study information will be kept in a locked file cabinet. If the results of this research are published or presented at scientific meetings, your identity will not be disclosed. The researcher will contact you to confirm the date, time and place for the interviews.

Please sign if you agree.

I have read and understood the information sheet. I know that I will answer questions about my care giving experiences on my child with chronic pain. I have received a copy of this agreement.

I (please print name) _____ give my consent to take part in this study.

Participant's signature: _____ Date: _____

Researcher's name (in print): _____

Researcher's signature: _____ Date: _____

APPENDIX H: Informed Consent-Participant Information Sheet (Setswana)**DITSELANA TSA TUMALANO YA PATLISISO**

O kopiwa go tsaya karolo mo patlisisong e. Mokwalo o o latelang ke yo o go fang molaetsa ka patlisiso e. Pele fa o tsaya tshwetso, bala o tlhaloganye mokwalo o o fa tlase, mme o ka botsa dipotso fa o sa tlhaloganye. O gakololwa gore ga o tlamege go tsaya karolo mo patlisisong e.

Setlhogho sa dipatlisiso: Maitemogelo a Batlhokomedi ba bana ba ba dingwaga tse thataro go ya ko go tse di lesome le borataro (6-13years) ba ba tshelang ka ditlhabi mo mmeleng.

Mmatlisisi le mogala: Gomolemo Oodira (72150259)

Maikaelelo a patlisiso: Go tlhaloganya maitemogelo a batlhokomedi ba bana ba ba dingwaga tse di magareng ga borataro le lesome le boraro ba ba tshelang ka botlhoko mo mmeleng ka bophara.

Go tla sekasekwa gore a o fitlhelela ditsamaiso tsa patlisiso e. O tla a botswa dipotso tse di go amang. Go solofela gore potsoloso ya ntlha e tseye metsotso e e fa gareng ga 45-60.

Potsoloso e nngwe e tlaa latela fa mmatlisisi a feditse go kanoka patlisiso, se e le go netefatsa puisano ya gago. O tlaa botsolotswa kwa lefelong le nako e e go siametseng jaaka ko lapeng, mo sepateleng kana kae fela fa go go siametseng, mme o gakololwa gore lefelo e nne le le sa kgoreletseng puisanyo ya rona.

O tlaa kopiwa gore potsoloso e tsewa mantse. Ga go bonolo go phuthologa go buwa ka tse di agileng mo pelong ya gago, ja lo o ka nna le go kgoberego maikutlo le letsapa. Batlhokomedi le badiri ba lephata la botsogo ba tla a nna le sebaka sa go dirisa molaetsa wa patlisiso e. O tlaa nna le kgoreletsego fela ya nako ya gago ya potsoloso. Ga go na dituelo.

O letlelesaga go ikogogela morago mo tumalanong ya go tsaya karolo ka nako nngwe le nngwe fela wa ntle ga dituelo. Ga go na sengwe se se ka dirisiwang go lemotsha gore puisano ke ya gago. Mmatlisisi le mokaedi wa gagwe ke bone fela ba ba tla itseng ka patlisiso e. Sekapa mantse, ditumalano le mekwalo yotlhe di tlaa bolokwa fa go babalesegileng.

Fa maduo a patlisiso e a ka anamisiwa, kana a dirisiwa mo bokapanong jo bo faphegileng jwa dipatlisiso, ga go na go dirisiwa leina la gago. O tlaa leletswe ke mmatlisisi, gape go ka dirisiwa mokgwa wa puisanyo e o e supileng gore re dumalane ka letsatsi, nako le lefelo la potsoloso.

Ke tlhalogantse ditselana tsa patlisiso e. Ke tlaa araba dipotso tsotlhe ka maitemogelo a me a go tlhokomela ngwana o o tshelang ka botlhoko mo mmeleng. Ke amogetse moriti wa tumalano e.

Ke le (kwala leina la gago) _____ ke a dumalana go tsaya karolo mo patlisisong e.

Monwana wa mo tsaya karolo: _____ Letsatsi: _____

Leina la mmatlisisi: _____ Monwanawammatlisisi _____ Letsatsi _____

APPENDIX I: Child Assent-Participant Information Sheet (English)

Title of the Study: Experiences of Caregivers of Children (6-13years) with Chronic Pain

Principal Researcher and Telephone Number: Gomolemo Oodira (+26772150259)

Aim of the study: To seek an in depth understanding of experiences of caregivers of children (6-13 years) with chronic pain.

I am carrying a study to understand the experiences of people who take care of children with chronic pain. You are one of the children with chronic pain who is taken care of. If you agree, your caregiver will be asked some questions about experiences of caregiving. You will not be interviewed. You can discuss it with your parents or relatives. If you have questions about this study, you can ask me at any time.

You will not be paid for being in this study. The interview will be private and confidential; no one will get to know about it without your permission. However if the results are published, your names will not be used. There are no risks directly to you, but your caregiver can have emotional upsets and fatigue, and will be appropriately taken care of.

If you sign this paper, it means that you have understood that your caregiver can go ahead with the study. By not giving permission, no one will be upset if you change your mind later.

Your signature: _____ Date _____

Your printed name: _____ Date _____

Signature of person obtaining consent: _____ Date _____

Printed name of person obtaining consent: _____ Date _____

*If verbal assent only is being obtained:

Put initials here if child cannot sign, to document that child received this information and gave assent verbally: _____

APPENDIX I: Child Assent-Participant Information Sheet (Setswana)**DITSELANA TSA TUMALANO YA GO TSENELELA PATLISISO**

Setlhogo sa Patlisiso: Maitemogelo a Batlhokomedi ba bana ba ba dingwaga tse thataro go ya ko go tse di lesome le borataro (6-13years) ba ba tshelang ka ditlhabi mo mmeleng.

Mmatlisisi le mogala: Gomolemo Oodira (72150259)

Maikaelelo a patlisiso: Go tlhaloganya maitemogelo a batlhokomedi ba bana ba ba dingwaga tse di magareng ga borataro le lesome le boraro ba ba tshelang ka bothoko mo mmeleng ka bophara.

Ke eletsa go batlisisa ka go tlhaloganya maitemogelo a batlhokomedi ba bana ba ba dingwaga tse di magareng ga borataro le lesome le boraro (6-13 years) ba ba tshelang ka bothoko mo mmeleng ka bophara. O mongwe wa bana ba ba tshelang ka jo ne bothoko jo.

Motlhokomedi wa gago ke ene fela a tla a botsolotswang dipotso. O ka buisana le batsadi, ba losika kana mongwe fela ka patlisiso e. Fa o na le dipotso, o ka mpotsa nako e nngwe le nngwe. Ga go na dituelo.

Dikgang tsa patlisiso e, ke sephiri sa rona, ga gona yo o ka itseng fa e se wena o letlelela mongwe. Le fa go ntse jalo, maduo ke one a ka anamisiwang mme go sa dirisiwe maina a gago. Go ka nna le kgoberego maikutlo fa motlhokomedi wa gago a botsolotswa, mme go na le thulaganyo ya go mo thusa.

Fa o dumalana, go raya gore o tlhalogantse, mme motlhokomedi o ka tswela pele ka patlisiso. O ka fetogela tumalano ya gago nako nngwe le nngwe, mme ga go na yo o ka go bonang molato.

Ba ya monwana
(ngwana): _____ Letsatsi _____

Leina la ngwana: _____ Letsatsi _____

Monwana wa yo o dumalanag le tumalano ya ngwana: _____ Letsatsi _____

Leina la yo o dumalanang le tumalano ya ngwana: _____ Letsatsi _____

Fa ngwana a dumalana fela ka molomo a sa kgone go kwala:

Supa ka ditlhaka tse dikhutshwane go supa gore ngwana o amogetse molaetsa e bile o a dumalana:

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

APPENDIX J: Budget

A. TYPING	UNIT COST	TOTAL COST
Final Study Proposal	70 pages@ P10 per page	P700.00
Corrections on Final Study Proposal	70 pages@ P10 per page	P700.00
B. PHOTOCOPYING	Sub-Total	P1400.00
Letters of permission to conduct the pilot study and the final study	10 copies@ P1 each	P10.00
Interview guide for pilot study	6 copies@P1 each	P6.00
Interview guide for study	15 copies@P1 each	P15.00
Correction of final study	4 copies, 70 pages@ P1.00 each	P280.00
Final study	8 copies, 70 pages@ P1.00 each	P560.00
	Sub-Total	P871.00
C. TRANSPORT AND MEALS	UNIT COST	TOTAL COST
1. Pilot Study		
Molepolole to SLH, and back	P5.00*2 days*2	P20.00
Meals	P30.00*2 days	P60.00
2. Final Study		
Molepolole to SLH, and back	P5.00*20 days*2	P200.00
Meals	P30.00*20 days	P600.00
	Sub-Total	P800.00
D. SUPPLIES	UNIT COST	TOTAL COST
Pens	5*P5.00	P25.00
Pencils	2*P2.00	P4.00
Highlighters	4*P15.00	P60.00
Lined Papers	5 reams@ P30 each	P150.00
Rubber	2*P1.50	P3.00
Laptop	1*P3500.00	P3500.00
Audio-video	P1500.00	P1500.00

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CHRONIC PAIN

Batteries	6*P10.00	P60.00
USB	1*P100	P100.00
Floppy Diskette	5*P15	P75.00
Note Books	2*(200 pages)*P20	P40.00
	Sub-Total	P5517.00
E. BINDING	UNIT COST	TOTAL COST
1. Study Proposal	8 copies@P80	P640.00
2. Final Study	8 copies@P100.00	P800.00
	Sub Total	P1440.00
	Grand Total	P10082.00