

**The family caregivers' experiences of caring  
for home-dwelling older people with faecal incontinence**

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## DECLARATION

I certify that this work does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: .....

Date : .....

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## LIST OF ABBREVIATIONS & DEFINITION

<b>ADL</b>	Activities of Daily Living
<b>BPS</b>	Badan Pusat Statistik (Central Statistical Bureau of Indonesia)
<b>CASP</b>	Critical Appraisal Skills Programme
<b>CHCC</b>	Community Health Care Centre
<b>Ditjen Dikti</b>	Direktorat Jendral Pendidikan Tinggi Kementrian Pendidikan dan Kebudayaan (Directorate-General of Higher Education, Ministry of Education and Culture)
<b>NHMRC</b>	National Health and Medical Research Council
<b>IAD</b>	Incontinence-Associated Dermatitis
<b>ICS</b>	International Continence Society
<b>Kepmenkes RI</b>	Keputusan Mentri Kesehatan RI (The decree of Health Ministry of Indonesia)
<b>Depkes RI</b>	Departemen Kesehatan RI (Health Ministry of Indonesia)
<b>MRSA</b>	Methicillin-resistant Staphylococcus Aureus
<b>Posyandu</b>	Integrated Health Post (for older people)
<b>PHC</b>	Primary Health Care
<b>Puskesmas</b>	Health Care Centre
<b>Respite</b>	Short-Term Care Place
<b>SBREC</b>	Social and Behavioural Research Ethics Committee

## **ABSTRACT**

### **Background:**

Faecal incontinence is a health condition and ageing is the most common predictor of it. Faecal incontinence is associated with high levels of care burden and is a major reason for institutionalised care for older people in developed countries. However, in Indonesia, older people with faecal incontinence usually live at home and are cared for by their children who are influenced by culture and tradition. Therefore, family caregivers play a major role in caring for aged family members who suffer from faecal incontinence who may experience high levels of care burden. Globally, studies concerning caregivers' experiences are scarce and none have been conducted in the Indonesian context.

### **Aim:**

This study aims to understand the experiences of family caregivers who provide care at home for older people with faecal incontinence. It also examines their perceptions of the enablers and barriers that shape their practice.

### **Methodology and Methods:**

An interpretive phenomenological approach, underpinned by Gadamer's philosophic hermeneutics, was chosen to address the purpose of this study. Participants consisted of 10 family caregivers who cared for older family members with faecal incontinence. The data was collected using semi-structured interviews.

**Results:**

The findings are summarised in six themes: (1) minimizing the detrimental impacts of faecal incontinence on the care recipient; (2) incontinence aids; (3) a lack of information and education about faecal incontinence care; (4) a lack of healthcare services for home-dwelling older people with faecal incontinence; (5) support for caregivers; and (6) caregiver motivations. In theme one, the care strategies used to manage faecal incontinence are odour management, maintaining hygiene, skin protection, time adjustments, and managing diet. Traditional herbal medicines, such as coconut oil, were used to maintain skin integrity. Theme two revealed that disposable pads were preferred by most of the study participants. The lack of proper disposal management of continence aids raised issues of environmental pollution. Theme three highlighted that caregivers with insufficient information about how to care for older people with faecal incontinence impeded their practice. The information they needed centred on practical issues such as managing diet and how to assist older people with the activities of daily living. Theme four revealed that healthcare services for frail older people with faecal incontinence have not been developed in the Community Health Care Centres. Theme five revealed that social and cultural traditions had influenced how family members were chosen as primary caregivers. These primary caregivers usually shared their care load with other family members. Finally, theme six indicated that caregivers were motivated by spiritual values. The spirituality and religious beliefs of the participants played an important role in reinforcing their sense of duty.

**Conclusion:**

The lack of care services, information, and support for caregivers in the Community Health Care Centres impeded family caregivers' performance in the care of older people with faecal incontinence. This situation had a detrimental impact on care recipients and caregivers.

**Key words:** faecal incontinence, family caregivers, home-dwelling older people, environment, primary care

# CHAPTER 1: INTRODUCTION

## 1.1 Introduction to Thesis and First Chapter

This thesis is about caregivers' experiences of caring for community-dwelling people with faecal incontinence in Indonesia. Chapter One presents the introduction to the study which includes an introduction to faecal incontinence, the study background, an overview of healthcare provision for community-living older people in Indonesia, the aims and research questions, the methodology and methods and the significance of the study. In the last part of this chapter, the structure of the thesis is described.

Faecal incontinence is not a disease, but a symptom or a co-morbidity of other health conditions. According to the International Continence Society (ICS), faecal incontinence is "*The involuntary loss of flatus, liquid, or stool that is a social or hygiene problem*" (Chatoor et al. 2007, p. 134; Potter et al. 2007). Another more specific definition of faecal incontinence is "*continuous or recurrent uncontrolled passage of faecal material (more than 10 mL) for at least one month in an individual older than three years of age*" (Lazarescu, Turnbull & Vanner 2009, p. 30). Some risk factors of developing faecal incontinence are obstetric trauma; anorectal abnormalities; neurological disease; various cancers; inflammatory bowel disease; bowel surgery; psychological problems; infections; reactions to medications, drugs, or diet; anal fistula; haemorrhoids; immobility; chronic constipation; diarrhoea; obesity; type 2 diabetes mellitus; and functional limitation (Matthews et al. 2013; Whitehead et al. 2009). Old age is a common predictor of faecal incontinence (Markland et al. 2010; Matthews et al. 2013; Roslani et al. 2014).

Faecal incontinence is a hidden problem, as many people who have the condition do not report it to health professionals. Studies have revealed that the prevalence of faecal incontinence in community-living older people range from 2.9% to 19% (Aslan et al. 2009; Brittain et al. 2006; Nevler 2014; Quander et al. 2005; Teunissen et al. 2004). However, the predicted number can be underestimated as people with faecal incontinence tend to keep the problem secret (Atarodi, Rafieian & Whorwell 2014; Harari 2009).

Due to the significant impact of faecal incontinence on older people and their caregivers in community settings, this health condition should be properly managed. Faecal Incontinence Associated Dermatitis (IAD) (Bliss et al. 2011; Nix & Haugen 2010) and pressure ulcers (Chacon et al. 2009; Park & Kim 2014; Wilczweski et al. 2012) are some of the adverse effects of faecal incontinence. These are also associated with higher levels of burden (Kamel, Bond & Froelicher 2012). They also negatively affect the quality of life of older people and their caregivers (Walter et al. 2011). Hence, providing care services for older people with faecal incontinence, and supporting family caregivers in the Community Health Care Centres (CHCC), are measures which are strongly recommended as having a potentially positive impact on their health status (Adashi, Geiger & Fine 2010; Ingram et al. 2012).

Regardless of the importance of managing of faecal incontinence, caring for people with the condition is expensive. A study conducted in the United Kingdom revealed that each patient needed 52.2 minutes and about \$27 per day for their incontinence care (Borrie & Davidson 1992). Similarly, a more recent study conducted in Australia showed that each patient needed 109 minutes and \$AU49 per day for their incontinence care (Morris et al. 2005). If time is converted into the money equivalent, the total amount of money needed would be

even more significant than in the presented findings. Xu et al. (2012) argued that the severity of faecal incontinence is also strongly related to the total expenses over an entire year. The study of people with faecal incontinence in community settings in the USA highlighted that the annual expenses amounted to \$4,110 or around \$12 per day per person (Xu et al. 2012). Hence, incontinence care, including faecal incontinence, amounted to a large cost burden.

## **1.2 Study Background**

The prevalence of older people with faecal incontinence in the community setting is high. However, one study reported that the prevalence rate for older people with faecal incontinence in the community was lower than that in long-term facilities (McGrother 2005). This may be true in developed countries, as faecal incontinence is a major reason for admission to aged-care facilities (Brown & Abdelhafiz 2011). However, Potter et al. (2007) argued that, in developing countries, the majority of people with faecal incontinence are living in the community. For instance, in Bali, Indonesia, the only study that has revealed the prevalence of faecal incontinence in Indonesia, the prevalence of faecal incontinence was 22.4% among older people aged 60 or over in the community (Suyasa et al. 2014). It is obvious that the prevalence of community-dwelling older people with faecal incontinence is very high. Thus, CHCCs in Indonesia should pay attention to this group of people and their family caregivers to ensure that this health condition is managed well in the home care environment.

The social-cultural-historical context of Indonesia has placed great importance on informal caregivers in regard to the care provision of older people. In recent decades, the increase in the number of older people in Indonesia has increased significantly. Based on the 2010 census (the most

recent census in Indonesia), Indonesia is among the top five countries in terms of numbers of older people (Depkes RI 2013a). It is predicted that the ageing population will reach 36 million in 2030 (Depkes RI 2013a). As faecal incontinence is related to ageing, it is estimated that the number of people with faecal incontinence will also escalate (Brittain et al. 2006; Cerdán-Santacruz et al. 2014; Wallace 2008; Whitehead et al. 2009). Influenced by the culture and tradition, older people in Indonesia prefer to live in the community alone, or with their children whether in rural or urban areas (Cameron 2000; Kadar, Francis & Sellick 2013; Schröder-Butterfill, Fithry & Dewi 2010). This living arrangement predicts that older people with faecal incontinence will primarily depend on informal caregivers to manage the condition in Indonesia.

The quality of life of older people with faecal incontinence living in the community is determined by high-quality management of the problem. A study conducted in aged-care facilities in Korea demonstrated how faecal incontinence has a negative impact on quality of life (Joh, Seong & Oh 2010). One study also argued that people with faecal incontinence have a lower quality of life than those with urinary incontinence (Stenzelius et al. 2004). Poor management results in a low quality of life as it leads to a number of detrimental impacts of the faecal incontinence. Thus, the quality of care provided by the caregiver determines the quality of life of older people with faecal incontinence. The caregiver must have sufficient knowledge of faecal incontinence management in order to provide high quality care.

Faecal incontinence also results in an economic burden for the individual, the family, and the public (Cerdán-Santacruz et al. 2014). In developed countries, where older people are subsidised by the government such as in Australia, faecal incontinence care adds a financial burden to the entire country. In



contrast, in developing countries such as Indonesia, the financial burden is fully borne by the caregivers or the family, because caring for older people is viewed as the responsibility of the family in Indonesia rather than the government's responsibility as funded by taxpayers (Cameron 2000). It can be assumed that the burden of care of community-living older people with faecal incontinence in Indonesia will also be carried by the family in the near future as this situation is unlikely to change.

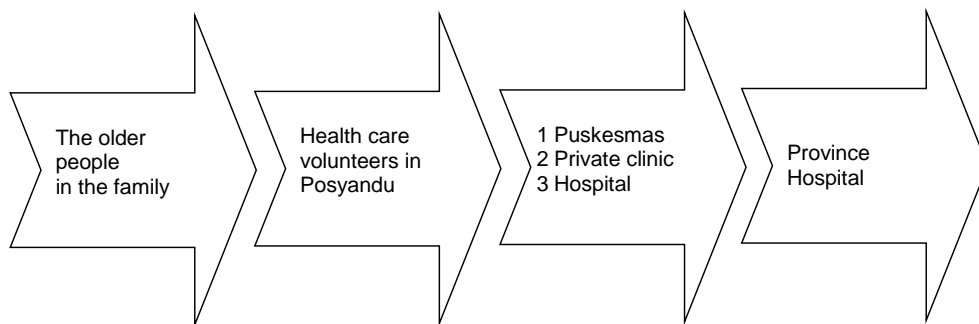
In relation to healthcare services in the community for older people, the Indonesian government provides Health Care Centres (Puskesmas) as well as Integrated Health Posts for older people (Posyandu Lansia) (Kadar, Francis & Sellick 2013). A brief description of how these two community healthcare resources are related to each other is presented below (Section 1.3).

### **1.3 Healthcare provision for community-dwelling older people in Indonesia**

Since 1968, Indonesia has acknowledged the concept of Puskesmas as an institution that is responsible for organizing the first level of service for people in the community (Kepmenkes RI 2004). In its work, Puskesmas has four principles: area-based responsibility, and the three principles of people-empowerment, integration of services, and referral (Kepmenkes RI 2004). One of the main concerns of Puskesmas is the health of older people in the community. Through these four principles, Puskesmas aims to distribute equal and affordable services to people in the community (Kepmenkes RI 2004).

In the coaching area of Puskesmas, there are a number of community-based services, such as Posyandu Lansia (Kepmenkes RI 2004). In fact, there are 69,500 Integrated Health Posts for older people (Posyandu Lansia) across Indonesia (Depkes RI 2013b). The existence of Posyandu Lansia provides

evidence of the people-empowerment principle for services for older people in the community, because each Posyandu Lansia is primarily self-supporting and operated by local people from that particular community. For example, each Posyandu Lansia has its own healthcare volunteers who come from the local area. The referral process (Kepmenkes RI 2004) for older people to healthcare services in their community, such as the Posyandu Lansia, until they reach the Puskesmas, is described in the diagram below (Figure 1):



**Figure 1 The health service referral process in the community**

The Puskesmas is equipped with healthcare professionals, such as nurses and doctors. However, to be able to cover the community as a whole, health professionals are assisted by healthcare volunteers (Kadar, Francis & Sellick 2013). As can be seen in the above diagram, Posyandu Lansia are the services that are the closest to older people. It can also be seen that the healthcare volunteers in the Posyandu Lansia play an important role as mediators between the family and the Puskesmas. The healthcare volunteers know the people in the community better than the healthcare professionals as they work and live in the same neighbourhood as the people (Kadar, Francis & Sellick 2013). Therefore, healthcare volunteers make a significant contribution to the caring process and the quality of life in the community.

Both Puskesmas and Posyandu Lansia are different in term of function and facilities. Some Puskesmas are supported with better equipment and specialist doctors and nurses, while Posyandu Lansia are only supported with very limited equipment and perhaps one general practitioner and a nurse. Also, Posyandu Lansia only provide services once a month; in contrast, Puskesmas provide services six days a week (Monday-Saturday). Posyandu have their own limitations in service provision for the community, because the services only focus on the prevention or optimization of older people's conditions. These centres only provide simple examinations, such as blood glucose and blood pressure checks which are primarily conducted by healthcare volunteers who do not necessarily have a health education background.

Considering the impact of faecal incontinence on older people and their family caregivers in the Indonesian socio-cultural context, research into the experiences of family caregivers is important in order to identify services and supporting mechanisms for this cohort of the population. However, the literature shows that no research has been conducted on this cohort in Indonesia. Therefore, this study is considered to be the first study to explore the experiences of caregivers for community-dwelling older people with faecal incontinence in Indonesia.

#### **1.4 Significance of the study**

Faecal incontinence relates to social isolation, a poor quality of life of older people, and a high level of caregiver burden. The lack of research into caregivers' experiences in caring for older people with faecal incontinence in Indonesia impedes the planning and development of services to support community-dwelling older people with faecal incontinence and their caregivers. This study, through investigating caregivers' experiences of caring for older

people with faecal incontinence in the home, will provide evidence to inform service development in Community Health Care Centres in Indonesia.

The purpose of exploring the experiences of caregivers is to better assess the supports that are needed for family caregivers, and the improvement of the quality of care for home-dwelling older adult as a final outcome. The ultimate goal of this study is to inform service development in the Puskesmas and Posyandu Lansia in Indonesia, for older people with faecal incontinence and their caregivers. This study will enrich an understanding of the challenges that family caregivers face when giving care to older people with faecal incontinence in the community setting in the Indonesia social, cultural, and religious context.

### **1.5 Aims and research questions**

This study aims to understand the experiences of family caregivers who provide care for older people with faecal incontinence in the home, through the following specific questions:

- a. What constitutes care for older people with faecal incontinence in home care environments?
- b. What are caregivers' perceptions of the enablers and barriers to their practice in managing faecal incontinence in the home?

### **1.6 Methodology and methods**

With the aim of understanding people's experiences, this study has opted to use a qualitative research design (Polit & Beck 2012). Interpretive phenomenology, which focuses on the significance of personal experience, was used to answer the research questions (Polit & Beck 2012). More specifically, this interpretive phenomenology study utilised Gadamer's philosophical

hermeneutics as the methodology. This approach requires a strong understanding of the socio-historical context to collect and interpret the collected data (Polit & Beck 2012). Gadamer (cited in Palmer 1969) argued that in order to interpret a person's experiences, the socio-historical context cannot be separated from the research process. This study used interviews as a method of collecting the data, a method commonly used in interpretive phenomenological research (Polit & Beck 2012). Using a fusion of the researcher's prior knowledge and the participants' stories, the researcher was led to a new understanding of the participants' experiences.

## **1.7 Thesis Structure**

This thesis consists of six chapters. This chapter introduces the general concept of faecal incontinence, the background to the study, an overview of the healthcare services that exist in the community (the Puskesmas and the Posyandu Lansia), the research question and study aims, a brief section on the research methodology and methods, and the significance of the study.

The review of the research literature on faecal incontinence management in the community, and the role of the caregiver for community-dwelling older people is included in Chapter 2. This chapter describes the literature search strategy and a critical appraisal of the literature. The categories identified from the literature review are the management of faecal incontinence, the burden experienced by caregivers, and an exploration of the social and culture-based values of caregiving.

A discussion of the chosen methodology and methods are presented in Chapter 3. This chapter explains the essential characteristics of Gadamer's hermeneutics approach namely: prejudice, the hermeneutical circle, and tradition. This chapter also includes the reasons for using this approach; the

methods of data collection, and data analysis, as well as a discussion of the rigour of the study, and the ethical considerations.

The findings of this study are presented in six themes, as follows: (1) minimizing the detrimental impact of faecal incontinence on the care recipient; (2) incontinence aids; (3) the lack of information and education about faecal incontinence care; (4) the lack of healthcare services for home-dwelling older people with faecal incontinence; (5) support for caregivers; (6) and caregivers' motivations. In order to assist the reader to gain a deeper understanding about the findings, the demographic characteristics of the carers' are also presented in this chapter.

Next, a discussion of the research findings is presented in Chapter 5. This chapter includes a discussion of faecal incontinence care services in community settings, the core knowledge and skills required by the caregiver to provide faecal incontinence care, support mechanisms for caregivers to cope with stress and the burden, and the need for written resources in the Indonesian language about faecal incontinence care. In addition, a comparison between the findings of the present study and those of previous studies will be presented.

Chapter 6, the final chapter, includes a summary of the main findings of the study. As well, in this chapter, recommendations will be made based on the discussion of the findings. Recommendations will be made for policy-makers, healthcare services, nursing practice, nursing education, family caregivers, and community organizations. Finally, the limitations of the study, and a reflection on the research journey will be presented.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter presents a review of the current literature on the family caregiver, with a specific attempt to capture the family caregiver's role when caring for older people with faecal incontinence and its management in the community setting. The literature review mainly aims to analyse those research studies which involve caregivers of people with faecal incontinence as their study participants. However, as faecal incontinence is a co-morbidity of other health conditions, the literature review also included the caregivers of people with conditions that are related to faecal incontinence. The literature review includes a description of the process for searching the research literature, a critique of the articles, an analysis of the findings, and a presenting of the findings in an organized format based on an integrated classification. The review aims to establish what research on the management of faecal incontinence has been conducted in the community setting, the challenges the family caregivers face, and the enabling factors of conducting the caregiver role.

### **2.2 Framework used to structure the review**

A literature review is an integration and evaluation of research articles that relate to a particular topic (Richardson-Tench et al. 2011). This is a useful process which is needed to make sense of research findings (Polit & Beck 2012). There are a number of processes involved, namely: searching, reading, sorting, analysing, and critiquing the articles, arranging the search outcomes in a logical order, and then summarizing them (Polit & Beck 2012). In order to integrate findings across a number of studies, frameworks such as a meta-

analysis for quantitative research, and a meta-synthesis for qualitative research are used (Polit & Beck 2012). The final results of a literature review are the insightful findings and patterns in the previous research (Polit & Beck 2012). A good literature review should clearly present the most recent findings, themes, and gaps in the research (Pryczack & Bruce 2007, cited in Richardson-Tench et al. 2011).

Using a thematic analysis, the articles in this literature review are grouped into various themes (Appendix 1). The thematic analysis made it easier for the researcher to find the discrepancies and similarities in the previous studies which were relevant to the research questions of this study. The strengths and weaknesses of the reviewed research articles have also been analysed (Appendix 2).

## **2.3 Article search and selection process**

### **2.3.1 Search strategies**

The primary resources for searching the research articles were the following electronic databases: CINAHL, Medline, PubMed, AgeLine, and Google scholar. The literature was searched using the following keywords: 'faecal incontinence', 'fecal incontinence', 'bowel incontinence', 'older people', 'frail elderly', 'aged', 'caregivers', 'carer', 'family', 'relatives', 'caregiver's experiences', 'activity daily living', 'caregiver's burden', 'caregiver's role strain', and 'management'. To limit the number of articles retrieved, selection was bounded through the inclusion criteria and exclusion criteria discussed below. In addition, because the number of articles was not sufficient, a manual search through the retrieved articles was also used.



### 2.3.2 Selection criteria

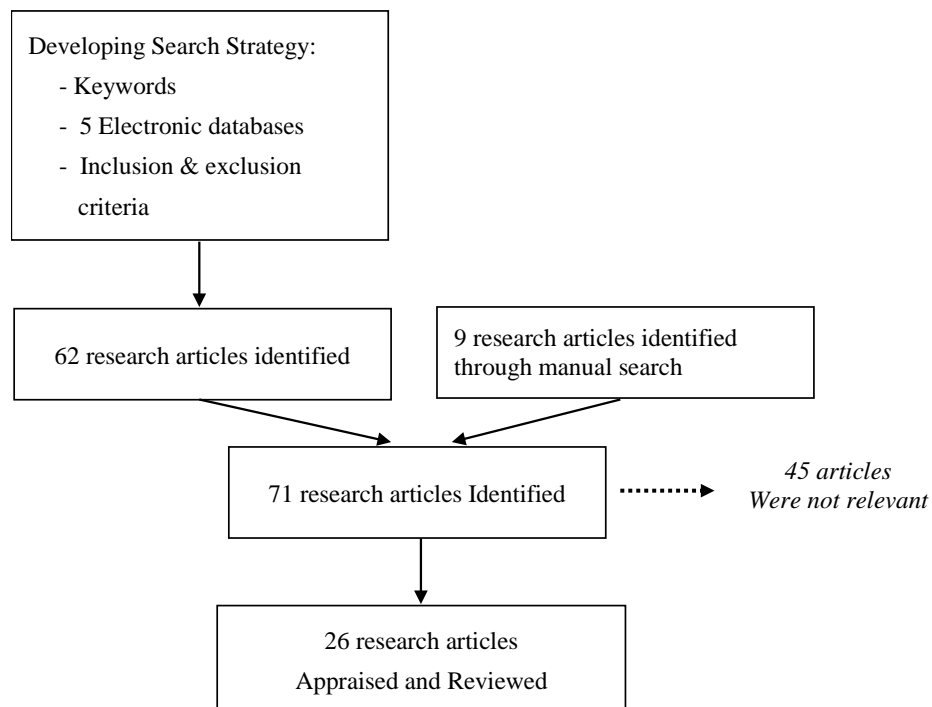
Due to the scarcity of the research articles about caregivers of people with faecal incontinence (Drennan et al. 2012), the criteria were set carefully in order to obtain a wide range of relevant articles. One of the strategies used was to include the research that was possibility related to faecal incontinence, such as articles about caregivers of stroke survivors, dementia, frail older people, and people with terminal illnesses.

**Table 1 Inclusion & exclusion criteria for searching of articles**

Inclusion Criteria of Article Searched	Exclusion Criteria of Article Searched
<ul style="list-style-type: none"><li>- Year 2003 to the present</li><li>- English and Indonesian language</li><li>- Articles that have older people as the participants</li></ul>	<ul style="list-style-type: none"><li>- Articles that have children as the participants</li><li>- Articles about incontinence that include only people with urinary incontinence without faecal incontinence</li></ul>

### 2.3.3 Search outcomes

By reading through each abstract and using the keywords and the selection criteria, 62 articles were found. In addition, in order to obtain more relevant research articles, a manual search was also conducted. Relevant studies published before 2003 were also included. There were nine articles found through the manual search. Overall, there were 71 research articles found; however, after the appraisal process of carefully reading the content of the articles found, a final total of 26 articles were chosen for inclusion. 19 of these are quantitative studies, six are qualitative, and one article is a mixed-methods study. The literature selection process is shown in Figure 2.



**Figure 2 Overview of the critical appraisal of the study**

## 2.4 Overview of the critical appraisal of the articles

Before the articles were included in the review, they were evaluated by using a number of appraisal tools to determine the quality of each article. This literature review used the Critical Appraisal Skills Programme (CASP 2013) tool for qualitative studies and the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal tool for quantitative studies (Newhouse et al. 2007). The CASP offers tools for critical appraisal (CASP 2013), while the Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal tool was developed by a team from the Johns Hopkins Hospital and the Johns Hopkins University School of Nursing in the United States of America (Newhouse et al. 2007). In addition, for the mix-methods article, the CASP tool was used.

Through the article review process, information regarding studies about faecal incontinence was obtained (Appendix 3). However, there were only five

studies that related directly to faecal incontinence management, one about incontinence in general, two about caregivers of people with incontinence, and only two studies directly relating to caregivers of people with faecal incontinence. In addition, most of the studies about caregivers were not directly related to faecal incontinence, even though some of them revealed that the difficult part of caring activities are in assisting with bowel elimination (Chong et al. 2014; Drennan et al. 2012). This process confirmed that the research on faecal incontinence is scarce (Drennan et al. 2012).

Overall, a broad understanding about the topic of faecal incontinence management was gained. Regarding continence-aids, none of the studies were conducted in Indonesia. In fact, most of the studies were conducted in high-income countries such as the United Kingdom and the USA, which present a different scenario to what happens in lower-middle-income economies like Indonesia (The World Bank 2014). Moreover, none of the studies were conducted in Asian countries, which may have a more similar culture to Indonesia. Obviously, more research on faecal incontinence management in Asian countries is needed.

Furthermore, there were no studies about caregivers of older people with faecal incontinence conducted in Indonesia. The only study about caregivers conducted in Indonesia was not focused on faecal incontinence, but instead on older people in general. The studies about caregivers depicted that usually, they were children or spouses of the care recipients (Cassells & Watt 2003; Chan & Chui 2011; Sánchez-Ayénde 1998). These studies were similar to the context found in Indonesia, where older people are cared for by their children at home. Having said this, research about the management of faecal incontinence by informal caregivers, especially in Indonesia, is also necessary.

The limitations of each reviewed study was also summarised (Appendix 3). Some of the studies had small sample sizes, and in others, sample bias existed. In quantitative studies, the larger the sample size, the more representative of the population the findings will tend to be (Taylor, Kermode & Roberts 2007). Generalizability will also be affected if quantitative studies have small sample sizes (Bliss et al. 2011). In some of the studies, even though the sample size was large enough, the samples were not randomly selected. Moreover, most of the studies used cross-sectional designs which were unable to explore causal relationships in the data (Schneider et al. 2013). As well, some of the studies used an internet-based research method and sample bias was evident. As a result, the results may not be generalizable (Gotoh et al. 2009). Finally, some of the articles did not mention the ethics considerations or how the ethics committee approved their studies, which is a crucial part of conducting studies on humans. According to Holloway and Freshwater (2007), ethics approval is needed to demonstrate that a study does not harm or present any risks for the participants, but instead provides a benefit for them or for wider society.

The findings from the literatures cover three areas: (1) The management of faecal incontinence; (2) The burden experienced by the caregivers; and (3) Socially- and culturally-constructed caregiving. These findings are discussed in the following sections.

## **2.5 The Management of Faecal Incontinence**

A number of studies conducted in both developing and developed countries showed that basic absorbent continence aids were used widely in faecal incontinence management in the community. In Colombia, 96% of study

participants reported using anorectal dressings, while 70% used sanitary pads, while the rest used panty liners, and briefs (Bliss & Savik 2008). Most of the participants used anorectal dressings because these were best able to absorb stool effectively and to reduce the smell (Bliss & Savik 2008). In the United States, the use of absorbent products appeared to be a common practice to manage faecal incontinence among older people in the community (Bliss, Fischer & Savik 2005). The findings of both of these studies were consistent with a study conducted in the United Kingdom (Bliss et al. 2011), where up to 45% of participants with higher severity of faecal incontinence used absorbent products. Among the study participants, the absorbent products were replaced between one and three times a day (Bliss et al. 2011). Size, shape, material, ability to control odour, and leakage prevention capacity were the aspects of absorbent products that concerned most of the respondents (Bliss et al. 2011). These studies revealed that most people in the community were familiar with absorbent products as a tool to contain stool and to reduce odour.

Two quantitative studies (Bliss, Fischer & Savik 2005; Croswell, Bliss & Savik 2010) and one qualitative study (Peden-McAlpine, Bliss & Hill 2008) indicated that people in the community were managing their diet in order to deal with their faecal incontinence. The study found that people avoided fatty foods, spicy foods, caffeine, alcohol, dairy products, and instead consumed lots of vegetables (Croswell, Bliss & Savik 2010). As well, many people created a consistent eating schedule (Croswell, Bliss & Savik 2010). Diet management appeared to be the second most important approach to managing faecal incontinence in the community.

The other tools used for faecal incontinence management were disposable wipes and gloves. A controlled trial study that was conducted in Los

Angeles which showed that these two tools were preferred by care workers in nursing homes (Al-Samarrai et al. 2007). However, the research found that there was a tendency for excessive use of both of these tools in nursing homes. For economic purposes, it was suggested that only three or four wipes should be used for every cleaning activity (Al-Samarrai et al. 2007).

Despite the usefulness of absorbent products, diet management and other aids, such as wipes and gloves, it was found that faecal incontinence was not managed well in the community (Bliss, Fischer & Savik 2005; Bliss et al. 2011). Some of the reasons which contributed to this situation included the severity of faecal incontinence, people's preferences, discomfort caused by the absorbent products, feelings of shame, lack of information, and high cost (Bliss et al. 2011). Lack of information about faecal incontinence by health professionals, and feelings of shame towards faecal incontinence were found to be the main predictors of poor faecal incontinence management in the community (Peden-McAlpine, Bliss & Hill 2008). Moreover, Bliss et al. (2011) pointed out that the severity of faecal incontinence determined people's eagerness to search for help from healthcare providers. The literature revealed that misperceptions about faecal incontinence often stop people from seeking help from health professionals.

Previous studies have found that the use of absorbent products, and changing diet and eating patterns, were the main approaches used in managing faecal incontinence in the community setting. Nevertheless, the lack of knowledge about faecal incontinence and its management has been the main factor in dealing with the problem. Consequently, this has resulted in poor management of faecal incontinence. The research indicated that people in the community primarily sought information from healthcare professionals. The

next section presents the analysis of the articles about the caregivers' experiences in performing their caring role.

## **2.6 Burden experienced by caregivers**

Caring for older people with faecal incontinence is challenging. The recent studies pointed out that assisting older people for their personal hygiene associated with defecating is considered to be difficult and unpleasant, and was a task that affected the caregivers negatively (Chong et al. 2014; Drennan et al. 2012; Haley et al. 2009; Holdsworth 2013). A study of 75 caregivers of stroke survivors pointed out that the caregivers described helping people with their bowel elimination as the most stressful aspect of assisting with Activities of Daily Living (ADL) (Haley et al. 2009). Furthermore, other studies indicated that faecal incontinence has a strong relationship to diarrhoea and pressure ulcers (Finne-Soveri et al. 2008), and that it is also related to urinary incontinence (Sørbye et al. 2009). It is considered challenging because the caregivers need to maintain the quality of life of care recipients with complex health conditions (Sørbye et al. 2009).

Caring for people with faecal incontinence requires a significant contribution from caregivers. It demands a greater amount of caring time from either care workers, nurses, or from informal caregivers (Finne-Soveri et al. 2008). Informal caregivers work on average about 38.83 hours per week for people with faecal incontinence, while only 18.36 hours are needed for people who have no faecal incontinence (Finne-Soveri et al. 2008). The caregivers who give more time to caregiving activities experience higher levels of burden and more drawbacks than those who give less time to such activities (Garcés et al. 2009). In general, caregivers dedicated a lot of time for caring for people with

faecal incontinence, and the more time they dedicate, the higher the burden will be. Furthermore, two studies (Garcés et al. 2009; Haley et al. 2009) found that caregiving tasks are more difficult when the care recipients' condition is worse. Hence, faecal incontinence is a major reason for admission to aged-care facilities (Grover et al. 2010).

Usually, faecal incontinence is present because of a number of possible contributing factors, such as functional decline (Finne-Soveri et al. 2008; Grover et al. 2010), cognitive impairment such as dementia (Finne-Soveri et al. 2008; Garcés et al. 2009; Grover et al. 2010), severe chronic illness and immobility (Grover et al. 2010). One study pointed out that the dependency of care recipients for their ADLs might also increase the caregiver's mortality risk (Brown, SL et al. 2009). Nevertheless, Brown et al. (2009) also argued that care recipients' cognitive impairment was unrelated to caregivers' mortality. From these findings, it can be seen that faecal incontinence among older people contributed to a higher level of burden on family caregivers, as it is related to people's ADLs.

A number of studies have been conducted to capture the burdens for informal caregivers of older people with faecal incontinence. These tasks often overwhelmed caregivers, and at some point, brought physical and psycho-social burdens to caregivers (Butler et al. 2005; Cassells & Watt 2003; Drennan et al. 2012; Garcés et al. 2009; Haley et al. 2009; Holdsworth 2013; Sarkar & Anand 2013; Tang, Li & Liao 2007). Physically, it was shown that caregivers may experience problems such as sleeping issues (Cassells & Watt 2003) and health issues (Sarkar & Anand 2013; Tang, Li & Liao 2007). Psychologically, they may experience stress and depression (Butler et al. 2005; Tang, Li & Liao 2007) as well as mental exhaustion (Sarkar & Anand 2013). Socially, they may feel



isolated and lonely (Cassells & Watt 2003). Moreover, caring for older people with faecal incontinence also resulted in a financial burden for family caregivers (Cassells & Watt 2003; Sarkar & Anand 2013; Tang, Li & Liao 2007). Thus, the caregiving role has negative impacts in many aspects for caregivers.

Nevertheless, Holdsworth (2013) argued that the psychological aspects were most affected by caregiving duties.

Furthermore, a study conducted among 62 caregivers in a rural area of New England state in the USA, identified that between 50% and 60% of participants experienced some kind of burden in addition to depression (Butler et al. 2005). Caregiving activities for older people can result in a high burden and depression for caregivers in different ways. Caregiver burden resulted from the difficulties of the caregiving tasks, while depression resulted from the social isolation (Butler et al. 2005). In addition, this study found that new caregivers were at risk of experiencing burden and depression because the caregiving tasks were not easy to do (Butler et al. 2005).

On the other hand, it was found that caregiving had both negative and positive aspects. One qualitative study on family caregivers of people with dementia showed that caregivers reported emotional tension when assisting care recipients to defecate (Drennan et al. 2012). They tried to respect their care recipients while trying hard to manage the bowel elimination privately (Drennan et al. 2012). Due to the caring duties, 41.33% of participants in another study reported that they experienced some strain, 14.67% a lot of strain, while 44% reported no strain (Haley et al. 2009). It is interesting that Haley et al. (2009) identified that almost 50% of study participants found no strain, while 99% of the study participants found a sense of meaning from their caring roles. Overall, it was revealed that caregiving can also benefit caregivers.

Garcés et al. (2009) highlighted that the caregivers' internal and external factors play a vital role in determining the burden. The caregiver's internal factors were their level of education, age, health status, and gender (Garcés et al. 2009; Holdsworth 2013). On the other hand, caregivers' external factors, such as the number of caregiving tasks, family issues, their local environment, and living with the care recipient, were considered to also determine the burden (Garcés et al. 2009; Holdsworth 2013). In addition, less support from other family members also increased the burden (Holdsworth 2013). This occurred especially if there was not a good relationship between the potential caregivers and the person being cared for (Holdsworth 2013). Therefore, examining the magnitude and quality of the internal and external factors is important. Moreover, one study found that negative feelings towards care recipients appeared when caregivers were not supported by others (Garcés et al. 2009).

The quality of the relationship also affects the resilience of caregivers in providing care. Chan & Chui (2011) emphasized that if the caregivers and the care recipient do not have a good marital relationship, the burden will be higher (Chan & Chui 2011). On the other hand, a study of five older men and three older women, conducted in Australia (Cassells & Watt 2003), found that the responsibility of caring for the partner affected the quality of their relationship. This study pointed out that the marriage relationship had a significant impact on the caregivers' evaluation of the caregiving tasks. Consequently, it would then affect their perception of the caregiver burden. Love, dedication, lifelong friendship, and acceptance were found to be the foundation of good care by the study participants (Cassells & Watt 2003). Therefore, a good relationship between the caregiver and the care recipient resulted in positive perceptions of

the caregiving tasks. On the other hand, an abusive relationship between the caregiver and the care recipient in the past predicts a negative perception of caregiving, and is associated with higher caregiver burden.

A recent cross-sectional study of 6,442 spousal caregivers in Hong Kong highlighted that the severity of faecal incontinence determined the level of caregivers' stress (Chong et al. 2014). Therefore, in order to enable the caregivers to proceed with the caring activities, they need some support. Cassells & Watt (2003) suggested that caregivers needed practical information such as the type and costs of continence aids. Moreover, Chan & Chui (2011) highlighted the need for financial and social support. Thus, information, and financial and social support are considered to be common needs for caregivers.

Other than this, a number of studies also captured the usefulness of having paid caregivers. One study discovered that, because of the burden of personal care, 5.73% of spousal caregivers were helped by paid caregivers so that the effects of personal care on the spousal caregiver would be reduced (Chong et al. 2014). Moreover, the findings from Chappell's (2008) study indicated that 31% of 200 caregivers in Shanghai were paid caregivers. It was also found that paid caregivers have less stress than family caregivers (Chappell 2008). Two reasons for this, according to the study findings, were because the paid caregivers had shorter caring periods, and that they tended to have less worries about the care recipients (Chappell 2008). These two studies revealed that the existence of paid caregivers as an additional support for the family was useful. The interesting issue here was that the quality of the care and recipients' health were the same whether they were cared for by a family caregiver or a paid caregiver (Chappell 2008).

In relation to the caregiving burden, the recent studies above have found that managing faecal incontinence is challenging and can bring higher levels of burden to caregivers. However, the predictors of burden come not only from the nature of the caregiving task itself, but also from the caregivers' external factors. Yet, the burden may lessen if the caregiver receives support from others in their local environment. Previous studies have also pointed out that financial and social support and the presence of paid caregivers were found to be useful.

## **2.7 Socially- and culturally-constructed caregiving**

In Indonesia, and other countries holding collectivist cultural values, older parents are usually cared for by the family in the home. A study about three ethnic groups in Indonesia (Schröder-Butterfill, Fithry & Dewi 2010) indicated that it was still considered taboo to send older parents to a nursing home. People preferred to have children as their caregivers, as they were considered to be responsible for looking after their older parents (Schröder-Butterfill, Fithry & Dewi 2010). It would often automatically become their duty, especially for women. This study pointed out that a husband preferred to be cared for by his wife, while a mother preferred to be cared for by her daughter (Schröder-Butterfill, Fithry & Dewi 2010). It was believed that being female was more suitable for housekeeping and cleaning duties. Besides, the majority of Indonesian people hold Islam as their belief system (BPS 2010b) which strictly defines the value and roles of the different genders. However, this study also highlighted that, because of a number of circumstances, the presence of paid caregivers for the family has been accepted (Schröder-Butterfill, Fithry & Dewi 2010). In Indonesia, this highlights that the obligations of children and women were the main predictors in carrying out caregiving tasks.

The findings of the above study in Indonesia were supported by a study from Hong Kong (Chan & Chui 2011). In Hong Kong, a study of 101 spousal caregivers of older frail Chinese people (Chan & Chui 2011) indicated that culture has a significant impact on the caregivers' level of burden. Being a woman in a Chinese family would automatically place them in the role of caregiver (Chan & Chui 2011). Inevitably, women who strongly keep their traditional values have few options to refuse the role (Chan & Chui 2011). This study indicated that their fear of criticism from others forced them to deal with the stress through passive coping mechanisms. As a consequence, they experienced a heavier burden (Chan & Chui 2011). This study showed that caregiving is heavily influenced by cultural values.

Cultural motivations not only occurred in Asian countries such as Indonesia and Hong Kong, but also in Latin America. In Puerto Rico, a study of 30 family caregivers, 90% of whom were the children of the care recipient, found that some participants felt that the caring task was very difficult (Sánchez-Ayénde 1998). They found it difficult to manage the wide range of tasks, including the showering of older adults (Sánchez-Ayénde 1998). It was also found that they needed to assist the older people with their daily living activities and that they often attempted to merge these with their own activities (Sánchez-Ayénde 1998). In contrast, the study also indicated that 75% of participants did not feel depressed in conducting the caregiving activities (Sánchez-Ayénde 1998). This was because they accepted the task as part of their responsibility as children in the family, especially if they were women (Sánchez-Ayénde 1998) and they lived near their parents with no-one else to help them (Sánchez-Ayénde 1998). In this study, it was obvious that culture played a crucial role in caregiving.

The culture driven motivation was also confirmed by a study in Spain (del-Pino-Casado, Frías-Osuna & Palomino-Moral 2011). Among 1,284 family caregivers, it was acknowledged that their eagerness to conduct their caring duties enabled them to endure the difficulties (del-Pino-Casado, Frías-Osuna & Palomino-Moral 2011). Even though more than 60% of the participants provided care to older people for more than 40 hours a week, they still did their tasks diligently and consistently (del-Pino-Casado, Frías-Osuna & Palomino-Moral 2011). This study also pointed out that the spirit of sacrifice would then be maintained by the sense of the mutual relationship between the caregiver and the care recipients (del-Pino-Casado, Frías-Osuna & Palomino-Moral 2011). As a consequence, the impact on the subjective burden of caregivers was reduced.

Romero-Moreno et al. (2011) examined the caregiving motives of 166 family caregivers of people with dementia. The motives were grouped into two types: intrinsic motives which included the emotional bonding with the care recipients, religious beliefs, and personal values; while the extrinsic motives include their feelings of obligation, their values, and the expectations of the community in which they lived (Romero-Moreno et al. 2011). In this study, it was highlighted that caregivers with low intrinsic motivation and high extrinsic motivation would be more likely to be emotionally affected by the caregiving role (Romero-Moreno et al. 2011). It is obvious that intrinsic motivations are more important than external motivations. In fact, Romero-Moreno (2011) found that there was quite a significant number (36.7%) of caregivers in the community who had both low intrinsic and extrinsic motivation.

Socio-cultural and spiritual values and beliefs appeared to be strong motivations for carrying out caregiving tasks. Cultural factors can affect motivation both positively and negatively. In some cases, the culture might strengthen

motivation positively, yet other people only act as primary caregivers in a half-hearted manner because they feel obliged to do so by their culture.

## **2.8 Summary**

This chapter has discussed the current research on the topic of faecal incontinence in relation to the management and caregiving provision for community-living older people. The research indicated that absorbent products were used widely in the community, and also discussed the criteria for preferred absorbent products. As well, the use of disposable wipes and gloves as additional aids has been suggested. People in the community also managed their diet to prevent the faecal incontinence from becoming worse.

The research also revealed that the lack of faecal incontinence management in the community was the result of the lack of caregivers' knowledge, as well as the lack of resource support in the local environment. The challenges of performing caring duties, such as the care recipients' condition, family dynamics, and the caregivers' condition also affected the well-being of caregivers. However, they were often motivated by traditional values and filial piety. The main supports gained were from family members and healthcare professionals. Caregivers' knowledge, which mainly came from healthcare professionals, was also useful for increasing their self-confidence and decreasing their stress.

This literature review has shown that studies on faecal incontinence are scarce. Most of the retrieved studies were about faecal incontinence management, rather than about the caregivers. Fewer studies were conducted in Asian countries, while none were conducted in Indonesia. Hence, future research about faecal incontinence and caregivers is recommended.

The following chapter outlines the methodology and methods of the study, the data analysis, and the ethics considerations. In addition, the chapter will explain how the qualitative approach, underpinned by Gadamer's philosophical hermeneutics, was used to conduct the research.



## **CHAPTER 3: METHODOLOGY AND METHODS**

### **3.1 Introduction**

The review of the literature on faecal incontinence revealed that studies on family caregivers' experiences in caring for older people with faecal incontinence were scarce. In addition, not a single study was conducted in Indonesia. This study aims to understand the experiences of family caregivers who provide care for older people with faecal incontinence in the home in an Indonesian socio-cultural context, with two specific questions to be explored, as listed below:

- a. What constitutes care for older people with faecal incontinence in home care environment?
- b. What are the caregivers' perceptions of the enablers and barriers to their practice in managing faecal incontinence in the home?

This chapter will discuss the methodology, methods, rigour, and ethical considerations of this study.

### **3.2 Methodology**

Phenomenology is a qualitative methodology that fits well with research that aims to understand people's lived experiences (Streubert & Carpenter 2011). In order to address the aim of the present study, looking at the community setting in Indonesia within this particular socio-cultural context, a qualitative approach underpinned by Gadamer's philosophical hermeneutics was chosen. The characteristics of, and the reasons for choosing, this framework will be discussed in the following sections.

### **3.3 Gadamer's Hermeneutic Philosophy**

Gadamer's theory was influenced by Heidegger, an influential German hermeneutics (interpretive) phenomenologist of the 20<sup>th</sup> century (Palmer 1969). Gadamer expanded upon Heidegger's hermeneutics by proposing that "understanding" is the most important means of participation in, and engagement with, the world (Mootz III & Taylor 2011). Therefore, attempting to 'bracket' the inquirer's pre-understanding from the research is not necessary. Gadamer's theory of human knowing, grounded in a phenomenological thematic analysis of human activity, highlights the effectiveness of human consciousness (Gadamer 1981). Hence, Gadamer's theory emphasizes that prior knowledge is important in the interpretative process, and that it is impossible to have a deep understanding of something that we are not familiar with.

Unlike descriptive phenomenology, hermeneutic phenomenology is more than just describing and interpreting human experience from the perspective of the researcher. Hermeneutic phenomenology emphasizes the inquirer's pre-understanding of the socio-historical context of human experience when interpreting and understanding a phenomenon of interest (Polit & Beck 2012). Gadamer (cited in Palmer 1969) maintained that interpreting human experience is not simply the process of objectifying human experience by putting the historical background aside; rather, it is the process of interpreting human experience in its socio-historical context. Gadamer argued that the experience was bounded to its background; therefore, an understanding of the background would lead to a deeper understanding of the meaning of experiences.

Three characteristics of Gadamer's hermeneutics have influenced the researcher in interpreting caregivers' experiences. These are prejudice, the hermeneutical circle, and tradition, as discussed in the following sections.

### 3.3.1 Prejudice

Gadamer (cited in Morse 1994) claimed that two central points, prejudice and universality, played key roles in human understanding. First, prejudice is defined as prior knowledge as part of linguistic experience. According to Crotty (1998), prejudice as used by Gadamer refers to one's prior knowledge which has been formed in the past. Gadamer (1989) argued that prejudice was not always negative, but is instead refers to an estimation about the facts of a matter that take place before a complete assessment is made. Second, universality is defined as common human consciousness, and the things that humans have in common because they are linked to their social world. As a result, it is possible to understand the experiences of others (Morse 1994).

In using Gadamer's hermeneutics, the researcher was encouraged to first attempt to understand the topic being studied. Gadamer believes that the researcher's prior understanding would influence how they interpreted human experience and that it was impossible to bracket out this prior experience (Polit & Beck 2012). Gadamer (1989) also believed that when people try to understand something, their foregrounding and prejudice are involved in the process. To understand human experience better, a hermeneutist needs to create themes from his/her prior understandings (Debesay, Nåden & Slettebø 2008). This approach highlights the fact that the researcher needs to familiarize themselves with the objects being studied and their background.

However, the researcher should also be open to what the people being researched are saying (Polit & Beck 2012). Gadamer (1989) suggested that openness was needed, as stated below:

“Of course, this does not mean that when we listen to someone, or read a book, we must forget all our fore-meaning concerning the content and all our own ideas. All that I asked is that we remain open to the meaning of the other person or text. But this openness always includes our situating the other meaning in relation to the whole of our own meanings, or ourselves, in relation to it” (Gadamer 1989, p. 268).

By keeping one’s mind open, it is possible for the researcher to understand the event being described by the research subject through dialogue and conversation (Palmer 1969). In a research project using Gadamer’s hermeneutics, the researcher must pay attention to the participants with curiosity and openness to their words, as well as to their nonverbal expression (Debesay, Nåden & Slettebø 2008). This means that, besides having a prior understanding of the study object, the researcher’s openness can enhance the real meaning of the experiences. Prior knowledge and prejudice make it easier for the researcher to understand how difficult the caregiver’s role is, but with an open mind, the researcher gains the perspective of the caregiver (in this case) which may be different from the researcher’s initial prejudice.

### **3.3.2 The Hermeneutic Circle**

Briefly, hermeneutics is “interpreting the meaning of an object” (Schwandt 2011, p. 115). Meaning is transmitted from one person to another through the use of words (Crotty 1998). In order to understand the meaning, hermeneutics should be situated within the context of the words, such as the tradition and past history (Crotty 1998). In addition, Debesay, Nåden & Slettebø (2008) pointed out that, in order to understand the present, one should go through a circular process by involving his/her own prejudice.

The hermeneutic circle is a process that involves experience, prejudice, and context. The term ‘hermeneutic’ relates human experience to its socio-historical context, and is intended to bring the inquirer’s prejudice to the circle

in order to reach a historical consciousness of the experience (Mootz III & Taylor 2011). The inquirer's prior knowledge will guide the interpretive process that may change from time to time (Mootz III & Taylor 2011). The hermeneutic circle also makes it possible for the researcher to back-track to the previous step if needed.

Moreover, through the hermeneutic circle, an in-depth understanding can be gained. Hermeneutics aims to obtain an in-depth understanding of the human experience (Crotty 1998). In the hermeneutic circle, the interpreter will first look at the text in which the human experience is recorded, then will engage with the context of the text, and then return to the text (Crotty 1998).

Understanding the small pieces by comprehending the overview or the 'big picture' of the text, and conversely, is how the hermeneutic circle works (Crotty 1998).

Gadamer's hermeneutic circle makes it possible for the researcher to gain an in-depth understanding of the whole meaning of what the participants in a study have said (Polit & Beck 2012). As has been described previously in relation to gaining a better understanding of family caregivers' experiences, the researcher exercised her prior nursing knowledge about caring for people with faecal incontinence, while opening her mind in relation to potential new discoveries from the interviews with the participants, and from the analysis of the socio-cultural and historical context in Indonesia via the hermeneutic circle.

### **3.3.3 Tradition**

In Gadamer's work, culture has a strong influence on people's behaviour. Gadamer (cited in Mootz III & Taylor 2011) views custom and tradition as the authority that drive one's attitudes and behaviours. According to Gadamer (cited in Mootz III & Taylor 2011), tradition and prejudice add to

interpretation. In addition, prejudice is also the result of culture and individual experience (Mootz III & Taylor 2011). Gadamer (cited in Mootz III & Taylor 2011) believes that understanding is the formulation of language, history, and tradition. Understanding people's traditions and background leads to an understanding of a person's actions.

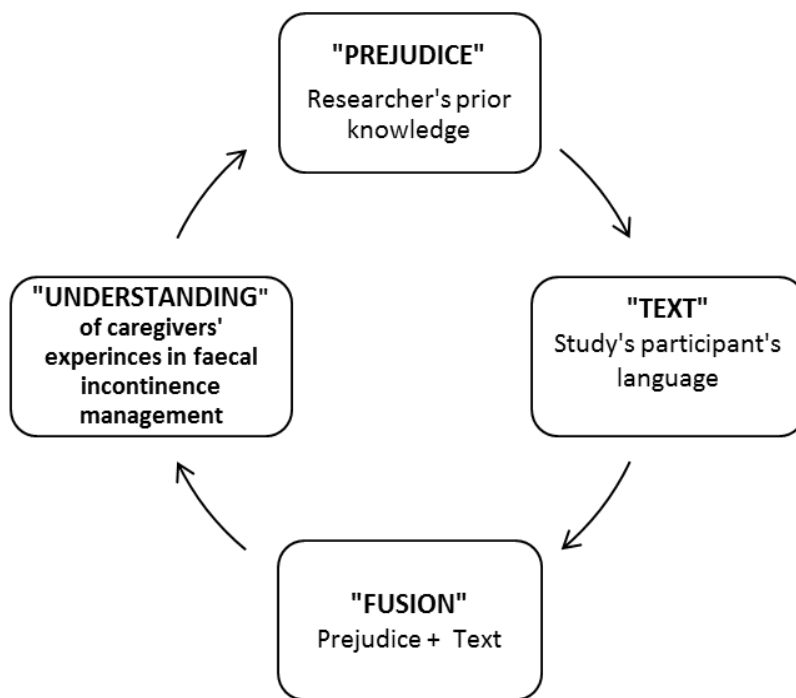
The researcher agrees with Gadamer that tradition plays an important role in the caregiver's actions. The researcher is interested in exploring how the experiences described by the participants are influenced by tradition, and also believes that caregivers' attitudes, behaviours, and actions in caring for family members with faecal incontinence are strongly influenced by Indonesian culture and tradition. Using Gadamer's framework made it possible for the researcher to understand caregivers' attitudes in their daily practices, especially in the Indonesian context with a strong cultural and religious background. As a result, when analysing the data, the researcher related the text to the study participants' background.

People have a range of certain points of view which is known as their horizon (Gadamer 1989). In order to understand tradition, a historical horizon is required (Gadamer 1989). Gadamer (1989) emphasizes that a fusion of the past and the present results in a better understanding, as stated below:

“If we fail to transpose ourselves into the historical horizon from which the traditionary [sic] text speaks, we will misunderstand the significance of what it has to say to us. To that extent, this seems a legitimate hermeneutical requirement: we must place ourselves in the other situation in order to understand it” (Gadamer 1989, p. 303).

Gadamer (1989) used the analogy of “put[ting] ourselves in someone else's shoes” as the way to grasp a correct understanding, in this case, the researcher needs to come to a more universal understanding that arises not solely from their own perspective. This analogy reflects that in order to

understand family caregivers' experiences, the researcher needs to build her understandings about caregivers' backgrounds, such as their traditions and the social context in which they live, as these are considered as driving their attitude and behaviours. Before the interviews began, the researcher attempted to attain some background information about the study participants. This information was used to build understanding during the interviews as well as in the data analysis. Figure 3 below provides a brief illustration that may help to understand how the researcher used Gadamer's Hermeneutic Approach.



**Figure 3 Illustration of hermeneutic circle**

### **3.4 The reason for choosing the framework**

Apart from the fact that Gadamer's framework is suitable for use in qualitative phenomenological study, more specifically, the researcher believes that this framework is best suited for this study. The researcher's nursing background will also be involved in the interpretative process.

The researcher has a theoretical understanding of the pathophysiology and management of faecal incontinence. As well, she also has experience of taking care of older people with faecal incontinence in hospitals as well as in nursing homes. This background will significantly contribute to the researcher's pre-understanding of caregivers' experiences when caring for older people with faecal incontinence. Such pre-understanding is the so-called 'prejudice' of Gadamer's Hermeneutics. The researcher believes that this prejudice enables her to approach and interview participants that are culturally and logistically appropriate for the study, and who reflect the tradition of the Indonesian context. The researcher also believes that this prejudice will enable her to reach an in-depth understanding of the participants' experiences through dialogues with participants about issues of concern and by relating the interview data to the socio-historical context; for example, the health care system, resources, and policies in Indonesia.

As pointed out above, it is difficult to bracket out the prior understanding (Polit & Beck 2012), the researcher believes that Gadamer's hermeneutic philosophy is the best framework to use. On the other hand, this prior understanding would help the researcher to gain a better understanding about the object of study (Gadamer 1989). In this study the researcher's knowledge and experience (prior understanding) in the care of older people with faecal incontinence influenced her performance in this study. The prior understanding was used to develop the semi-structured interview questions to gain more information from the participants. This prior understanding also helped the researcher understand the experiences of the research participants during the interviews and data analyses.



### **3.5 Ethical Considerations**

A rigorous study is also ethical sound and has no harm and risks for participants. The research implication for society is known as the political aspects of research (Elliot 2005). In order to balance the benefits of the research for the researcher and the participants, the researcher must set up an ethical framework (Holloway & Freshwater 2007). Therefore, this study follows the policy associated with the conduct of research that deals with human subjects in Australia, where the research proposal was developed, as well as in Indonesia, where the study was conducted.

In order to meet the ethics and political requirements of the study, the researcher prepared all the relevant documents before conducting this study. The Australian government, through the National Health and Medical Research Council (NHMRC 2007), has issued guidelines in a National Statement on Ethical Conduct in Human Research. The guidelines outline the ethical considerations that should be applied to research where human beings are participants. In addition, in Indonesia, every hospital has their own regulations about conducting research in their institution. This research proposal has been approved by the Social and Behavioural Research Ethics Committee (SBREC) of Flinders University, with the project number 6258 (Appendix 4), and has also been approved by Sint Carolus Hospital (Appendices 5 & 6). After approval was gained, the researcher began collecting the data.

After the ethical approval, the researcher approached some nurses in Sint Carolus Hospitals to distribute the information package to potential participants. The information package included the letter of introduction (Appendices 7 & 8), the information sheet (Appendices 9 & 10), and the participation response slip (Appendices 11 & 12). The nurse informants were expected to give the

participation response slips to the researcher. In fact, in most cases, the informant nurses only provided information about the potential participants. In such cases, the researcher directly explained the written information from the information sheet to the potential participants and asked if they agreed to participate in the study. The researcher also emphasized that participation in the study was voluntary, and that the participants were free to withdraw from the study at any time. When they had agreed to participate, the consent form was explained to the participants (Appendices 13 & 14) who then signed it.

The researcher assured the participants that participation in the study was confidential, that the research would be kept anonymous, and that any identifying information would be removed. This information was placed in an electronic voice file which was stored in a password-protected computer that only the researcher had access to. Once the researcher has finished reporting on the research, the voice recording would be destroyed.

### **3.6 Methods**

#### **3.6.1 Recruitment of participants**

In regards to sampling, unlike a quantitative study which considers the number and representation of the participants, a qualitative study is concerned about the richness of the information gained (Polit & Beck 2012). Furthermore, Norwood (2010) stated that data gathering in a phenomenological study has the objective of achieving a deep understanding about the object of study. Thus, this study does not have many participants. As well, Indonesia does not document the number of people with faecal incontinence, other than that found in Bali, which is only one area of Indonesia (Suyasa et al. 2014). This present study includes 10 participants as a phenomenological study commonly requires 5 to 8 participants (Boswell & Cannon 2014; Norwood 2010; Polit & Beck 2012).

A phenomenological study is concerned with the ability of the participants to communicate their experiences, and with the variety of those experiences (Polit & Beck 2012). Therefore, this study used purposive sampling guided by the inclusion and exclusion criteria found in Table 2.

**Table 2 The inclusion & exclusion criteria of study participants**

Inclusion Criteria of Participant	Exclusion criteria of Participant
<ul style="list-style-type: none"> <li>- Family member who cares for older people (aged more than 60) who have faecal incontinence and require assistance for activities of daily living</li> <li>- Primary caregiver who lives in the same house as the care recipient</li> <li>- Have been involved in the care activity for at least six months</li> </ul>	<ul style="list-style-type: none"> <li>- Do not have capability to express their experiences (for example, they have a problem with speaking or hearing).</li> </ul>

The researcher struggled to find participants as this study aimed to explore the experiences of family caregivers who care for their older family members in the home. The difficulties arose because there was no available data about people with faecal incontinence in the community. To overcome this issue, the researcher used a number of strategies to select the study participants.

Firstly, the participant selection process was started by approaching health professionals, such as nurses in the acute care hospital, to find older people who have faecal incontinence, while adhering to the inclusion and exclusion criteria. From the acute care setting, the researcher found one person who met the criteria and was willing to be a study participant. The other strategy taken was to approach the hospital home care unit. Using information from the nurses who delivered home care services, there were two participants who met the criteria and were willing to be study participants. The rest of the participants were directly recruited from the community setting.

This strategy was facilitated by one of the hospitals from which the researcher gained ethics approval. This hospital has a close relationship with the community around the hospital as they actively educate and assist the health care volunteers in the community. Through the information gained from one of the nurses in this hospital, the researcher found a number of healthcare volunteers who were willing to help the researcher to search for participants who met the inclusion and exclusion criteria. The researcher first provided brief and simple information about the participants required for the study. As the healthcare volunteers were lacking in knowledge about faecal incontinence, they sometimes failed to give the correct information about the potential participants. Thus, before consent was gained from the study participants, the researcher would ensure that they were appropriate study participants. Finally, 10 participants were recruited.

### **3.6.2 Data Collection**

Phenomenological research primarily uses interviews for collecting data (Polit & Beck 2012). An interview is also likened to a structured dialogue (Rubin & Rubin 2005). There is a variety of interview types which can be used, ranging from structured, through to semi-structured and unstructured interviews (Minichiello, Aroni & Hays 2008; Pope & Mays 2006). The structured interview uses closed questions which are carefully ordered, and usually, the same questions will be asked of each participant. As well, the researcher needs to maintain a distance from the participants in order to achieve a somewhat objective stance (Minichiello, Aroni & Hays 2008). The semi-structured interview focuses on rich information from participants in order to reach an in-depth understanding (Polit & Beck 2012). The structured interview is usually applied in quantitative studies using questionnaires or survey instruments, while

less structured interviews are used in qualitative research (Taylor, Kermode & Roberts 2007). The present study used semi-structured interviews.

### **3.6.3 Interview Structure**

The semi-structured interview requires the use of an interview guide. Through the interview process, the researcher wishes to grasp the perceptions, emotional states, and insights of the participants about past as well as future events (Holloway 2008). Further questions can be developed based on the responses of the participants, which can result in a different question order for each participant; thus, the researcher needs to use a guide to overcome the drawbacks of this issue (Holloway 2008). A guide is useful for obtaining similar information from all participants as well as for saving time (Holloway 2008). Using a semi-structured interview, the researcher is able to conduct an interactive conversation (Minichiello, Aroni & Hays 2008). The researcher used the aims of the research and a list of questions (Appendices 15 & 16) to create a guide that would garner as much information as possible given the time constraints of the interviews.

An interview is a combination of primary questions, follow-up questions, and probes (Rubin & Rubin 2005). Follow-up questions should aim to answer the research question (Rubin & Rubin 2005). Moreover, the follow-up questions and probes are used to enrich and clarify the data (Rubin & Rubin 2005). While conducting the interviews, the researcher kept the primary research questions in mind to help her to stay on track. However, when needed, the questions were broadened in order to gain a deeper and richer understanding from the study participants.

### **3.6.4 Interview Questions**

When conducting semi-structured interviews, the researcher needs to develop a set of interview questions. Moreover, the questions need to be developed in a logical order to encourage the participants to talk about their experiences through an interactive conversation with the researcher (Polit & Beck 2012).

Ten semi-structured questions were developed to address the two research questions above (Appendices 15 & 16). The first six questions aim to gain information about home-based care caregiver provided, while the last four questions aim to investigate the caregiver's perceptions of the factors that enabling and impede their practice in managing faecal incontinence in the home. These 10 semi-structured questions were used to guide the interviewer through the interview process, so that similar information could be gained from each participant.

In order to obtain rich information, the open-ended question is the best option (Rubin & Rubin 2005). In the semi-structured interview, the researcher uses open-ended questions, usually starting with the more generic questions, to make the participants feel comfortable (Pope & Mays 2006). In addition, the researcher should be open to any particular information from each participant that may enrich the data gathered during the interview.

### **3.6.5 The setting of the interview**

Some preparation is needed before each interview begins. First, the interviewer needs to memorize the questions so that they will be able to listen carefully and follow the conversation with maximum focus (Minichiello, Aroni & Hays 2008) on the participants' verbal and non-verbal responses (Minichiello, Aroni & Hays 2008). Usually, the formal interview is set up in

advance and audio-recorded (Holloway 2008). The interviewer also needs to create a research diary to combine personal and logical observations and explanations (Minichiello, Aroni & Hays 2008). It should be noted that an audio recording can only record the words but not the non-verbal expression, which can only be captured through a video-recording. Moreover, the interviewer also needs to consider taking batteries, a notebook and other useful incidentals to the interview; therefore, a checklist of required items can be useful (Polit & Beck 2012).

Before conducting each interview, the researcher prepared all the tools that would be needed, such as the voice recorder, batteries, and a notebook. These were placed in a bag that was used during each interview so that all the required tools could be easily checked every time the researcher conducted an interview. The researcher also documented a number of important factors during the interviews, such as non-verbal expressions, and the body language of the participants.

The environment also plays an important role in the interview process. An interview should be a relaxed interactive conversation (Minichiello, Aroni & Hays 2008). For this reason, the researcher needs to place herself at the same level as the participants and to choose an appropriate venue in which to conduct the interview (Polit & Beck 2012). The interview venue can be in the home, at the office, or in a coffee shop, but the important issues to consider are to maintain privacy and avoid interruptions so as to enable the gathering and recording of the data (Polit & Beck 2012). This present study used the participants' homes to conduct the interviews as this was considered to be the best venue for the participants as they could continue to observe and care for the care recipients.

There are a number of situations that can influence the results of interview. Trust is important in order to gain rich and in-depth information (Polit & Beck 2012; Rubin & Rubin 2005). It is advisable to begin with small talk at the start of each interview (Polit & Beck 2012). As the interview process could last for up to 60 minutes (Norwood 2010) while need full concentration (Minichiello, Aroni & Hays 2008), there may be the possibility that the interview will be interrupted by unwelcome distractions (Polit & Beck 2012). In the interviews for this study, when there were interruptions, such as a telephone ringing, the researcher asked the study participant whether he/she wished to continue or to choose another time. At the end of interview, the researcher ensured that she had obtained rich information by asking the participants if they had any other comments to make. Trust had been developed from the very beginning of the interview to make the participants feel comfortable.

### **3.7 Data Analysis**

Analysing the data for qualitative research is challenging. This requires much in the way of planning; for example, organizing, structuring, and obtaining the meaning within the data (Polit & Beck 2012). There are no general guidelines for qualitative research; every method has its own set of rules (Polit & Beck 2012). This also applies to the use of phenomenology (Boswell & Cannon 2014). However, in qualitative research, the data needs to be presented concisely and informative (Polit & Beck 2012). Hence, the way in which the researcher analysed the data would influence the richness of the data gained.

Data analysis is time-consuming (Polit & Beck 2012); however, it can be undertaken at the same time as the data collection. This allows the researcher to develop new questions as the data is gathered (Boswell & Cannon 2014). The researcher does not need to wait until all of the data collection process has been



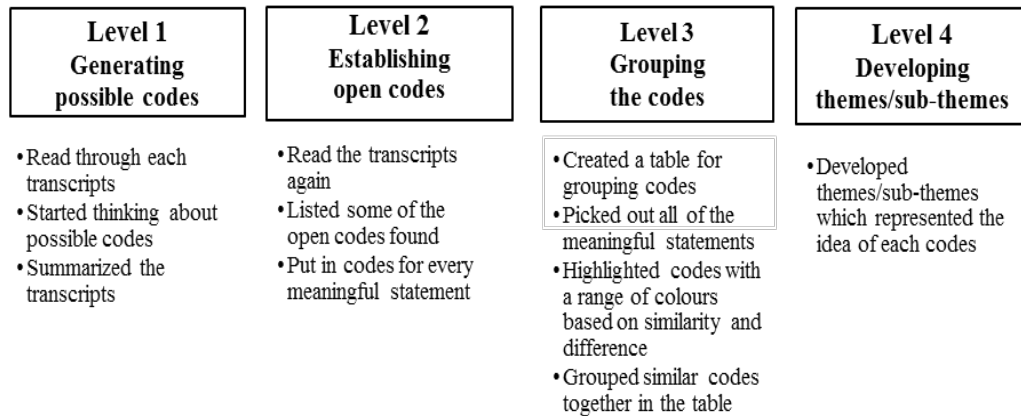
completed. In the present study, the analysis process began as soon as the data had been collected. Once the researcher had completed an interview, a summary of the interview was created in order to familiarize the researcher with the gathered data.

There are several tasks that need to be carried out in order to manage and organize the qualitative data, such as transcribing, categorizing, and coding (Polit & Beck 2012). In a phenomenological study, the analysis process proceeds through a general analysis, a content analysis, and then a phenomenological analysis (Polit & Beck 2012). The researcher who uses a phenomenological method should interpret the data without putting the entire context aside (Polit & Beck 2012). The researcher transcribed the voice recording. In order to grasp a deeper understanding about the data, the researcher also used field notes and a research diary to support the interview data. The researcher also asked the opinion of her research supervisors to check the quality of the data analysis over time.

Guided by Gadamer's Hermeneutic Circle, the researcher analysed the data mindfully and sensitively. Some of the steps taken were questioning, reflecting on, and validating the data (Polit & Beck 2012). The data was read by the researcher before grouping in the related codes, and putting the quotes under headings based on a range of categories (Polit & Beck 2012). Using the prejudice developed in the researcher's mind, the gathered data was reflected upon by the researcher. After this, using the field notes and the reflection log, the data was interpreted.

There were four levels of analysis conducted: (1) generating possible codes; (2) establishing open codes; (3) grouping the codes; and (4) developing

themes/subthemes, as described in Figure 4 below. The table used to group the codes as well as the themes/sub-themes is presented in Appendix 17.



**Figure 4 Levels of analysis conducted**

### **3.8 Rigour of the Study**

In qualitative research, rigour represents the value and accuracy of a study (Norwood 2010). The aspects that the researcher needs to consider in order establishing the trustworthiness of the research are: credibility, dependability, conformability, and transferability (Guba & Lincoln 1985).

#### **3.8.1 Credibility**

Credibility concerns the believability of the data and the accuracy of the interpretation of the data (Polit & Beck 2012). This study established the credibility of this research by applying the process recommended by Guba and Lincoln (1985). In this study, the researcher recorded the interview through the use of an electronic audio-recorder, so that the researcher would pick up all of the information. After this, the summary of the main points of the interview were sent to the participant to be validated. At first, a single transcript was translated into English which was then coded. This was sent to the researcher's

supervisors who evaluated whether the analysis and coding process were on the right track. Working with this feedback, the researcher followed the same process for the other interviews.

### **3.8.2 Dependability**

An audit trail is the best way to establish dependability (Munhall 2012). Dependability considers the consistency of a study over time, and the agreement between the coding and the themes (Polit & Beck 2012). In order to create an audit trail, the researcher included every piece of documentation, including field notes, the transcribed interviews (in the Indonesian language), the coding scheme, and the themes. For this study, there was a risk of error in the process of translation from Indonesian to English that may have influenced the results of the study. To eliminate this risk, the transcripts of the interview were translated by the researcher. In order to interpret the data, the researcher included some context under the text, so that the supervisors could understand whether the interpretation was correct. Using Gadamer's hermeneutics has encouraged the researcher to continuously reflect upon the text in relation to its context. As well, in the Findings chapter, the researcher included the participants' demographic data and a brief description of the participants' background as needed.

### **3.8.3 Conformability**

Conformability denotes the consistence between the interview data and findings (Polit & Beck 2012). A study is considered to have established conformability when it demonstrates an audit trail (Schneider et al. 2013). In this study, the conformability was achieved by including the participants in the analysis process where possible. The researcher gave the summary of the main

findings to the participants, who then double-checked the findings. Moreover, the researcher's supervisors evaluated the interpretation of the coding and the themes. In addition, findings were supported by excerpts of interview data.

#### **3.8.4 Transferability**

This criterion refers to the applicability of the research (Munhall 2012). This ensures that the data can be applied to another situation (Polit & Beck 2012) or that it aligns with external validity (Lapan, Quartaroli & Riemer 2012). The data achieves transferability when it can be generalized to other samples from the same population (Lapan, Quartaroli & Riemer 2012). In order to establish transferability in this study, the researcher provided information about the characteristics of the research participants as well as the setting in which the research was conducted. Furthermore, the research is reported upon in detail; include the policies, the healthcare system, and the resources relevant to the care of older people with faecal incontinence. Hence, the reader is able to come to the correct conclusions about the study, and how they can transfer the findings to a similar social context (Lapan, Quartaroli & Riemer 2012).

### **3.9 Summary**

This chapter has provided the methodology and methods used in this study. The justification of using a qualitative methodology, using Gadamer's hermeneutics, to address the aims of the research about the experiences of family caregivers of home-dwelling older people with faecal incontinence, has been explained. The ethics considerations and processes taken prior to data collection, the process of participant recruitment, and the data collection process which uphold the principles of research ethics have also been explored. The negative impacts of the research for the study participants and society have been

reduced by applying correct ethical procedures. The researcher has applied Gadamer's hermeneutic circle which linked the participants' words and experiences to their socio-cultural and historical background. The analysis process was conducted through four levels. In addition, the researcher attempted to achieve rigour by applying a number of actions that maintained the credibility, dependability, conformability, and transferability of the study.

The next chapter describes the six major findings of the study. The themes and sub-themes are presented with direct quotations from the participants for support. The participants' demographic data is described before the presentation of the themes in order to assist with an understanding of the participants' background.

## **CHAPTER 4: FINDINGS**

### **4.1 Introduction**

In the previous chapter, the methodology and methods used to collect, analyse, and interpret the interview data were discussed. This chapter presents the findings of the study. Gadamer's hermeneutics was used as a theoretical framework to guide the study, including the use of interactive conversations with the participants during the interviews, and a thematic analysis of the interview data to determine the themes and sub-themes. The researcher developed an understanding about the participants' experiences in caring for family members with faecal incontinence through numerous hermeneutic circles, and by relating the narratives from the participants to the socio-cultural and historical context of care practice in Indonesia. The researcher's prior knowledge about family caregiving practice in Indonesian culture, faecal incontinence, and experiences in caring for patients with similar health conditions, assisted with the process of data analysis and interpretation.

Six themes, and a number of sub-themes, were identified through the data analysis. These themes and sub-themes are summarised in Table 4 and discussed in the following sections of this chapter. In addition, the socio-cultural and historical aspects of the findings have also been summarised in Table 3, and discussed in the 'Discussion Chapter' in greater depth.

### **4.2 Caregivers' demographic information**

Ten family caregivers ranging from 19 to 82 years of age participated in this qualitative study. The majority of the participants (n=9) were female and had cared for the care recipients for at least 6 months. Six of the participants lived in a metropolitan area, while the rest lived in rural communities. The

caregivers who lived in the city acknowledged the *Posyandu Lansia* supported by the Indonesian government (Chapter 1). However, the program was also recognized by the participants living in the rural areas. The demographic information of the participants is summarised in Table 3.

**Table 3 Participant's demographic information**

Pseudonym	Gender	Age	Relationship	Socio-cultural backgrounds
Rina	Female	56 years old	Daughter	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Javanese cultural background</li> <li>- Only child for her mother</li> <li>- Has 2 adult children who were married</li> <li>- Lives in the capital city of Indonesia</li> </ul>
Ayu	Female	19 years old	Granddaughter	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Javanese cultural background</li> <li>- Single</li> <li>- Has graduated from high school and is preparing for a university entrance test</li> <li>- Lives in the capital city of Indonesia</li> </ul>
Juleha	Female	47 years old	Daughter in law	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Banten cultural background</li> <li>- Has one little grandchild cared for in the same house</li> <li>- Lives in Banten province (rural area)</li> </ul>
Dewi	Female	46 years old	Daughter	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Has mixed-cultural background</li> <li>- A wife and has a job</li> <li>- Has social activity as a volunteer in the integrated health care service</li> <li>- Lives in the capital city of Indonesia</li> </ul>
Budi	Male	82 years old	Husband	<ul style="list-style-type: none"> <li>- Catholic religion</li> <li>- Retired</li> <li>- Helped by two paid-caregivers</li> <li>- Lives in the capital city of Indonesia</li> </ul>
Tika	Female	29 years old	Daughter	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Sumatera cultural background</li> <li>- Single</li> <li>- Gave up her job because of the caring tasks</li> <li>- Lives in Banten (rural area)</li> </ul>
Dina	Female	44 years old	Daughter	<ul style="list-style-type: none"> <li>- A married-daughter with Moslem religion</li> <li>- Javanese cultural background</li> <li>- Has one younger child</li> <li>- Works as a lecturer</li> <li>- Lives in Banten province (rural area)</li> </ul>
Titut	Female	55 years old	Daughter	<ul style="list-style-type: none"> <li>- A single daughter with Moslem Religion</li> <li>- Javanese cultural background</li> <li>- Unemployed and spends most of her time at home caring for her older mother</li> <li>- She lives with her older mother, two sisters, and one brother with mentally illness</li> <li>- Lives in Banten province (rural area)</li> </ul>
Siti	Female	38 years old	Daughter	<ul style="list-style-type: none"> <li>- A single-daughter with Moslem religion</li> <li>- Mixed-cultural background</li> <li>- Works as a laundress in the morning</li> <li>- Look after her older mother and father</li> <li>- Lives in the capital city of Indonesia</li> </ul>
Misni	Female	61 years old	Neighbour	<ul style="list-style-type: none"> <li>- Moslem religion</li> <li>- Javanese cultural background</li> <li>- Lives with her husband, married-daughter and grandchildren at home</li> <li>- Lives in the capital city of Indonesia</li> </ul>

The influence of the socio-cultural backgrounds of the participants on their caregiver practice has been taken into account when using Gadamer's philosophical hermeneutic framework to interpret the participants' narratives. These influences are embedded in the presentation of the themes and sub-themes, and will be further discussed in the 'Discussion Chapter'.

### 4.3 Themes

This study has revealed six themes that are summarised in Table 4. These themes reveal the core components and meanings of caring activities that family caregivers provide on a daily basis, and the factors that enable or impede their caring activities.

**Table 4 Themes/sub-themes**

Themes	Sub-themes	Social, cultural and historical aspects
Theme one: Minimizing the detrimental impact of faecal incontinence on the care recipient	<ul style="list-style-type: none"> <li>- Odour management</li> <li>- Maintaining good hygiene</li> <li>- Diet management</li> <li>- Time adjustment</li> <li>- Protecting the integument</li> </ul>	Bathroom facilities; having relatives, friends and neighbour to visit the sick persons; Indonesian foods; water used to cleanse the dirty; expectation for the primary caregivers; traditional herb medicine or remedy
Theme two: Incontinence aids	<ul style="list-style-type: none"> <li>- Reasons for choosing or using continence aids</li> <li>- Continence aids disposal</li> <li>- Adaptation to repulsion</li> </ul>	Economic factors; water pollution in the river; State regulation regarding rubbish removal; the younger children looking after the older parents; the squatting toilet
Theme three: A lack of information and education about faecal incontinence care	<ul style="list-style-type: none"> <li>- Information-seeking</li> <li>- Caregiver's educational needs</li> </ul>	Lack information in Indonesia language; information provided by some hospitals
Theme four: A lack of healthcare services for home-dwelling older people with faecal incontinence	<ul style="list-style-type: none"> <li>- Health care services attention</li> <li>- Health services access</li> </ul>	Acute care dominated community care centres
Theme five: Support for caregivers	<ul style="list-style-type: none"> <li>- Support for caregivers from the family</li> <li>- Support from paid-caregivers</li> <li>- Family-dynamics</li> </ul>	Women as careers in the family; Moslem values; filial piety in Indonesian culture
Theme six: Caregiver's motivations	<ul style="list-style-type: none"> <li>- Responsibility/ duty</li> <li>- Filial piety led by female caregivers</li> <li>- The spirituality influenced caregiver <i>decision</i></li> </ul>	Program for the elderly people from mosques and churches



### **4.3.1 Minimising the detrimental impact of faecal incontinence on the care recipient**

When faecal incontinence is unable to be cured, the caregivers tried to maintain the dignity of, and comfort for, the care recipient, which also prevented them from developing further complications. The care strategies used by the participants to achieve these outcomes included odour management, maintenance of good hygiene, skin protection, time adjustments, and diet management. These strategies are explored below.

#### ***Odour management***

The participants struggled to eliminate odours with only limited resources. Maintaining the cleanliness of the home and keeping the environment free from odour was viewed as an important aspect of their care activities, in order to maintain dignity for the care recipient, for protecting the ‘face’ of the family in the neighbourhood, and for welcoming relatives and neighbours to visit the care recipient. They learned to use various strategies to maintain an odour-free environment for themselves and for the care recipient. As one caregiver stated:

*It's incredibly smelly in the morning, but then after showering, she will become clean and fragrant ... I must clean her up every morning; I will not let her become stinky (Juleha).*

Other participants also identified that bathing was an essential part of care to keep the person with faecal incontinence clean, comfortable, and free from odour. The participants saw this as necessary, regardless of the physical burden. In addition, Siti also strived to keep her father free from odour because of the stigma associated with faecal odour, as explained below:

*For the older people like my father, the most important thing is to keep him clean so that it will lessen odour. It is ashamed if our relatives or neighbour come to see him and smell odour. Right isn't it? (Siti).*

In Indonesia, many of the houses that were built a long time ago, regardless of their location, do not usually have shower facilities. Most people in Indonesia take a bath in the bathroom using a bucket to take water from the tub or a large container. Some of the participants brought the care recipients to the bathroom, making it possible for the participants to bathe their entire body. This type of bath is considered better than a bed bath. However, some participants had to give a bed bath to those care recipients who were bedridden.

Siti's feeling of shame if her father was not odour-free reflects the social context in Indonesia. It is common that relatives, neighbours, and friends often come to see the sick person who is hospitalized or suffers from a chronic condition. In order to maintain the family member's dignity and to protect the 'face' of the family in the community, it is essential for the caregiver to maintain a clean and odour-free environment.

The other strategies used by the participants to minimise odour, included timely changing of soiled continence aids and clothes, and the use of materials to contain the faeces, as Dina who cared for her mother stated:

*Normally, the diapers will be changed up to three times in a day. The cloth which applied on the top of the bed is replaced twice in a day ... there was a time when mother got diarrhoea, I was replacing diapers eight times in a day (Dina).*

Dina believed that keeping her mother's body clean and odourless was not sufficient to maintain fresh air in her mother's bedroom. She even took proactive measures to maintain a clean and odourless environment by using available resources as substitute air fresheners in the bedroom to make her mother feel comfortable, as stated below:

*After I open the diaper, I use wet tissue to clean up the faeces, and then I use soap, liquid soap ... for odour prevention is the reason why I use the liquid soap. I also put camphor in her bedroom so we will not smell odour in her room (Dina).*

Dina did not mention the reason why she used camphor instead of air fresheners in the bedroom, but some people used camphor to eliminate the odour as it is useful for neutralise an odour without adding a new smell. Moreover, another caregiver, Rina who was an only child in the family, and who had cared for her mother for some years, believed that the frequency of replacing continence aids was crucial for the prevention of odour. As she stated:

*But, if we replaced the cloth and the diapers often, it will not be stinky, I suppose ... I replace her diapers up to four or five times in a day, and check the diapers every four hours (Rina).*

Therefore, Rina and other participants checked the continence aids regularly and changed them accordingly.

Maintaining an odour-free environment is an essential part of the caregivers' activities. Activities such as bathing, maintaining fresh air in the room, changing soiled continence aids, and care of the recipients' clothing were conducted by the caregivers. It was also stressed that the frequency of undertaking such activities resulted in odourless care for the recipients and the environment; however, the caregivers were also concerned with providing good hygiene.

### ***Maintaining good hygiene***

Family caregivers made great efforts to maintain good hygiene for the care recipients. They believed that poor hygiene was associated with complications, such as diarrhoea and skin infections. One obstacle for maintaining hygiene can be seen from the following quote by Budi, in which the soap supplied for the caregivers was stolen by a rodent and other provisions had

to be made, as Budi, a husband who had taken care of his wife for two years stated:

*I know that for diarrhoea prevention, we need to keep hygiene ... and, for the paid-caregiver, they should wash their hands after disposing the diapers. I always provide cream soap for them to use. Previously, I provided bar soap, now I don't use it anymore because mice took it away (Budi).*

The participants also needed to think about some of the agents which cause disease. Titut, who cared for her mother with dementia, often gave her a bath after a faecal incontinence episode because her mother unconsciously touched the faeces and then other parts of her body. Although the activity added a significant physical burden for Titut, she thought it was necessary, as she stated in the following excerpt:

*I bathe over her whole body including hair. ... it's not only using soap for her body, but also shampoo ... she will be put on my lap, and my sister will pour the water over her body. Sometimes we need three persons to bathe her ... I need assistance from my sister, but when there is nobody helping; I will still do it alone (Titut).*

As mentioned above, most Indonesian people use a bucket for bathing; however, Titut found it difficult to hold her mother and the bucket at the same time, as well as the bar of soap which most people in Indonesia use for bathing. Since she usually bathes her mother's entire body, she needs both soap and shampoo. Having dementia, her mother also has difficulty in cooperating with her daughter's directions. There is no proper equipment for older people or people with dementia to sit safely in a bath or shower in bathrooms in normal Indonesian homes. There is a safety concern in Titut's case, and it is imperative for Titut to gain support from the community nurses to improve safety in the care activities.

Another participant, Siti, paid great attention to cleaning some of the parts of her father's body that she thought would be at high risk if contaminated

with faeces. Her father also had cognitive impairment. Based on her experiences, the parts of her parent's body which were at high risk of faeces contamination were the genitals and hands, as stated below:

*The number one concern is to clean his hands and bottom ... I'm afraid that he touches this and that. It is a must to clean those parts of body. I keep this part clean (Siti).*

Siti stated that her father touched his faeces with his hands and that this was unhygienic; other participants also understood this. In relation to hygiene, some participants showed how concerned they were in regard to hygiene by using hygiene aids, such as wet tissues containing an antiseptic. One participant also cleansed the anal area twice each episode using both an antiseptic wet tissue and soap and water.

*I also use soap even though it's only in small amount because my mom cares about hygiene. If I only use wet tissue, I think it's not as clean as using soap. I use the wet tissue twice (Dewi).*

The reason why some participants used antiseptic wet tissues as well as soap was because the person with faecal incontinence wanted them to do so, as Dewi explained, and because they knew the potential of unhygienic conditions leading to complications for their loved ones. Siti indicated that her father would have skin problems if she did not keep her father clean.

*I also use the antiseptic soap for I'm afraid that my father will get itchy ... you know, a baby will get itchy if we don't clean his skin, I believe it applies the same to the older people, even more (Siti).*

In order to minimise the detrimental impacts of faecal incontinence, and complications that could worsen the care recipients' health status, participants maintained hygiene. One of the ways in which the participants did so was to use water. In Indonesia, water is used for rinsing away the elimination products such as faeces and urine. Indonesian people usually use a bucket to collect the water and rinse their genito-urinary and anal area with water after elimination.

They even clean these areas with soap, especially after defecation. Providing hygiene and protecting care recipients from odour were not the only ways taken by caregivers to manage faecal incontinence. Diet management was also an effective way to control the problem.

### ***Diet management***

Participants were aware that faeces was the final product of the digestion process, with the smell, colour, and consistency of the faeces being influenced by what kind of foods and drinks were consumed. Some of the participants shared their experiences that some foods would produce ‘bad smells’ from faeces. Diet management was undertaken by some participants to deliberately avoid malodours.

*Oh, I also pay attention to mom’s food as well. For her faeces, I avoid giving her foods which affect it, like some foods which produce a strong smell to the faeces (Dina).*

Some participants believed that, through diet management, they could also prevent diarrhoea. Some foods were found to cause diarrhoea; for example, spicy and fatty foods. Misni explained her experience in diet management for a care recipient to prevent diarrhoea which would be an added burden for her.

*I had stopped giving her spicy food. If I put coconut milk into the food, I will put the light one. Papaya will not be given every day because I’m afraid it would cause diarrhoea which will make me busier (Misni).*

The findings indicated that the participants had knowledge that certain foods determined the incidence of faecal incontinence, diarrhoea, and the odour produced by the waste. The more frequently the faecal incontinence happened, the less comfortable it was for the care recipients, and also the more work for the caregivers. Carefully selecting the food played an important role in faecal incontinence management in caregivers’ activities.

Indonesia consists of more than 17,000 of islands (Hargo n.d.) as well as a wide range of different ethnicities that usually have their own cultural preferences for food. People from Sumatra like to eat spicy foods, while people from Java Island like sweet foods. Regardless of the taste, in general, Indonesian food consists of various ingredients which will influence the smell as well as the consistency of the faeces. Moreover, in some parts of Indonesia, people also like to add coconut milk to their vegetables, chicken, meat, fish, or eggs. This research was conducted in the capital city of Indonesia and the surrounding area, where the cultures are mixed, and their food preferences are not necessarily from their home town. Some of the participants who know about the impacts of food on faecal incontinence avoided particular foods.

Despite organising their own personal lives, caregivers devote much of their time for these meaningful activities for their older family members. The next section presents an overview of how they use their time in looking after their parents.

### ***Time adjustment***

In an attempt to provide comfort for the person with faecal incontinence, and to avoid complications, some of the participants struggled with time management and aligning their social life and other roles with that of the family caregiver role. For those participants who were younger and still socially active and engaged, the caring activities for their family members with faecal incontinence disturbed their normal activities. As Dewi, the daughter of a mother with dementia explained:

*I take care of my mother. Even though I'm in my business, I often come home to look after my mom, and then continue my social activities. Back and forth. I adjust my time ... I will come home every two or three hours. Why I must do that? Because I need to make sure that the faeces won't spread anywhere. The older people are like that, they defecate*

*unconsciously ... sometimes we don't know if mom touches her diapers when I am away from home as sometimes she wants to know whether she defecates or urinates (Dewi).*

Not all the family caregivers were as active as Dewi. One of the participants gave up their job due to their role as a primary caregiver, while another chose to work only a few hours in a location close to home. However, caring for an older family member with faecal incontinence took up a large part of their time because they felt the need to constantly be there.

*I can't leave her at home, I feel guilty to leave her home without me. I and mom are a unity ... If I should go away from home, I will go from home in the morning, and return back in the afternoon. I won't go away for a long time (Titut).*

The caregivers felt pressure in having enough time to care for the older people with faecal incontinence. They did not want to leave the person by themselves because of their reliance on their carer. Having the role of a primary caregiver is not easy because it carries a significant responsibility as the neighbours and the family assume that the caregiver knows everything about the care recipient's condition. This means that they will need to stand by at all times. As well, leaving their parents for a lengthy period often makes them feel guilty. The time burden that caregivers experience has implications for the development of community care services in Indonesia. A discussion of this issue is presented in the next chapter.

### ***Protecting the Integument***

Integument problems may arise from the presence of faeces in contact with the skin. To prevent the risk of skin complications, such as dermatitis, some participants tried to find ways to protect and treat the integument. Among the 10 participants, there were two who chose to apply coconut oil regularly as a



protective barrier rather than baby oil. Rina and Budi shared their experiences in using this oil.

*When mother was being hospitalised, nurses taught me to use coconut oil. That's why her skin condition is good. Before, I don't understand about this. There was a rash on her skin. To overcome this I have to change her position after some hours ... I apply coconut oil instead of baby oil because it is considered a more effective moisturizer than baby oil, moister ... I should apply the oil twice, morning after bathing and afternoon (Rina).*

*Next, to avoid skin injury, I use coconut oil. There is no injury on my wife's skin until now ... Coconut oil is cheaper and more effective than baby oil ... It's already proven. Many people have proven this. Everyone who came to visit my wife was surprised ... and you know, her skin has no wrinkled, in fact; she is eighty one years old. I don't know if it's the effect of coconut oil, but coconut oil does prove useful in preventing injury on her skin I suppose (Budi).*

Faecal incontinence causes problems for the integument when it is exposed to the faeces. The frail condition of older people also contributed to the complications of faecal incontinence, so they needed to be assisted to keep their skin healthy. Most caregivers have only limited knowledge, skills, and resources for protecting the integument. This sub-theme reveals the importance of caregiver support from community nurses in managing faecal incontinence.

Some people in Indonesia prefer to use natural resources rather than visiting the chemist, due to safety concerns for the care recipients. Traditional herbal medicines or remedies are still applied as some people believe they are safer and more effective. Therefore, the participants who had concerns about their family members' integument turned to traditional methods of handling this issue. In regards to coconut oil, this substance is famous in Indonesia for its benefits. It can be eaten, used on the hair and skin, and even the stem of the coconut is used for bridge building in rural areas. Furthermore, coconut oil is also easy to make and/or purchase.

### 4.3.2 Incontinence Aids

Regardless of the fact that there were several methods used to manage faecal incontinence, incontinence aids were the most well-known tool to use to manage the problem. The reasons for choosing incontinence aids were for easy disposability, and that they were used to help the carer and the care recipient to adapt to the sense of repulsion. These issues are discussed below.

#### *Reasons for choosing or using continence aids*

Continence aids were used either by the older family member with faecal incontinence or by the family caregivers as a means to protect them from the dirty faeces and/or the odour. Disposable pads were the most common continence aids worn by the older people to contain their faeces. As one participant stated in relation to diapers:

*I choose diapers as a practical continence aid. It can be thrown away after it is used. That's all that I need (Budi).*

Another participant chose disposable pads for religious reasons, as expressed by Juleha:

*I chose disposable pads to contain the faeces because it is cheap. That disposable pad is cheap. Nobody told me to use disposable pads; I learn by experience, I found it by myself. Even for my three-year-old grandchild I use disposable pads to contain the urine. I don't like if the floor become dirty. As a Moslem I need to pray (sholat) (Juleha).*

Moslem people need to keep themselves clean from dirty substances such as urine and faeces. If their body is contaminated by these substances, they need to bathe their entire body every time they want to pray (sholat). Moslem people need to pray five times every day. Tika struggled to find the best diaper for her older mother, the care recipient.

*It's just a little sharing. We all know that the older people are a little bit fussy. I think it's normal. My mom complained when she felt that the*

*diaper was uncomfortable. She would stop asking after we found the most comfortable one (Tika).*

Apart from the disposable pads, the family caregivers also applied rubber sheeting and cloth as mattress protectors to prevent the faeces from penetrating the bed when the diapers were no longer able to hold the faeces. One participant also used newspaper to protect the floor of the room from faeces.

*Even though she wears disposable pads, because she is old and has dementia, she sometimes unconsciously put off the pads that she said someone has put her pads off... Sometimes she sleeps not in the place she is supposed to be, so I put cardboard on the floor, and newspaper on the cardboard to protect the floor from faeces ... I think it is effective because it is practical and simple, it means that I don't need to wash many cloths (Misni).*

Although disposable pads were used by most of the participants, the cost of these pads was still a consideration when choosing continence aids. Since people with faecal incontinence need to wear the pads continuously, Siti did not use disposable pads for her mother.

*I chose cloth nappies instead of disposable pads. Disposable pads are costly, I cannot afford it. I will not force myself to care beyond my capacity (Siti).*

A variety of considerations influence how the family caregivers chose continence aids for faecal incontinence, such as the practicalities and the cost. Even though disposable pads were common incontinence aids, one in ten participants decided not to use diapers for financial reasons. Siti was one person who chose cloth nappies as her continence aid. It was ascertained from the participants that disposable diapers were the most common continence aid used. Siti could not afford disposable pads as she still required monthly support from her siblings. Washing the cloth nappies in the laundry space behind her house was not an issue for her, especially as she used the water for free.

Siti, who chose cloth nappies as continence aids for her father, found it difficult in the rainy season because she was reliant on the sunlight to dry them, as she explained:

*Because my father doesn't wear (disposable) pads, the problem will definitely occur in the rainy season. Sometimes we run out of cloths. We cannot manage it ... All that I do is hanging the cloths and clothes inside our house. We use rope like this (Siti).*

Siti managed this problem by creating a hang line in the family home, so that she could continue providing the continence aids for her father. She needed to do this for around six months of the year in Indonesia. In the past, before disposable pads were known to the public, people would use cloth nappies to contain the urine or faeces, or they just wore their underwear and changed it whenever it was wet. There is no historical data available about this.

For the participants who used diapers as continence aids, cost was one of the considerations, as they needed to provide the continence aids continuously. For those who lived in Jakarta, they had a preferred store for buying disposable diapers that was cheaper than the supermarket. The participants mentioned a market which was located in the centre of Jakarta as the best place to find continence aids. As Rina said:

*I buy the diapers in Pramuka Market, as it is cheaper than in the supermarket ... And now it's easy, I use the delivery order service. I just need to call them (Rina).*

Apart from the market providing her with cheaper aids, Rina was pleased that, in this market, she could also use the delivery service. This allowed Rina and a number of other participants more time and energy, so that they could put the time and energy to better use in taking care of their relative.

This sub-theme displayed the caregivers' unique experiences of continence aid provision. Any type of continence aid has its own benefits and

problems. This study demonstrated that the family caregivers strove to provide continence aids to meet the needs of their family members. Siti's case reflected that not all people in Indonesia can afford to provide disposable pads for family members who have faecal incontinence. In fact, Siti knew about the Pramuka Market as it was close to where she lived, but the financial cost made it difficult to provide disposable pads.

### ***Disposal of continence aids***

Disposing of continence aids (disposable diapers) was also an issue faced by the family caregivers who participated in this study. They tended to dispose of the diapers in a way that was detrimental to the environment, rather than to let their house environment become malodorous. Budi stated:

*If I keep the dirty diapers in the house, the house will become stinky. So I would throw it in to the river instead of keeping it at home ... The paid-caregivers usually throw the diapers away into the river when it's still dark, around five in the morning (Budi).*

In this scenario, the rivers would quickly become polluted by the dirty continence aids that take many years to break down and which contain faeces contaminated with microorganisms. Nowadays, the people of Indonesia get their drinking water from the state water company which they need to pay for. However, the disposal of the continence aids into the rivers shows that people are still not concerned about water pollution. Another participant chose to burn the dirty diapers which would instead pollute the air. Dina explained why she burned the dirty diapers.

*Because the waste will not be collected every day, I would burn the dirty diapers, so scavengers (persons who collect some reused garbage from the bin) could not make it messy ... After I put the diapers with the plastic bag, I usually go to a place where people throw their domestic garbage and burn them all there, it's near the river (Dina).*

*I'm now starting to think about what will happen if the state government cleans up the river. It is possible that they will make strict sanitation regulations and safeguarding. I could not imagine this (Budi).*

The caregivers continuously face this problem of disposing of the continence aids. Their disposal practices were considered harmful to the ecosystem and this was recognised by some of the participants. Although they knew that their actions endangered the environment, they thought this was the best practice available to dispose of the faeces.

This theme revealed the needs of continence aid provision, as well as for a disposal method that is eco-friendly. There is a need for knowledge of alternative continence aids and where they can be obtained from, as well as assistance for choosing the most suitable for a specific situation. The issue of garbage removal, such as the collecting schedule, and finding ecologically safe methods still pose many problems. The present situation is that people who need assistance with finding faecal incontinence aids and disposing of the faeces will search for information themselves without any other guidance. Secondly, although the government has introduced a mechanism for domestic garbage separation for recycling and non-recycling, this is not proceeding well. It is known that the government will collect the garbage, put it in temporary landfills, and later put it in the permanent landfills. This system needs to be well-managed as the current process resulted in the death of some scavengers who were buried by the garbage while searching for reusable items to make their living. This is the present situation for garbage removal in general, but not yet for faecal containment.

Regarding the concern about throwing pads into the river, recently the government has been dealing with flooding which has become a major problem in Jakarta. Budi, who lives in Jakarta, mentioned his concern that the

government would take serious action against people who throw the aids into the river.

### ***Adaptation to repulsion***

People know that faeces are dirty and odorous which not many can cope with. Professionals such as nurses who deal with urine and faeces are well-known as professions that do “dirty work”. It was understandable that even though the caregivers looked after their older family members as sincerely as they could, they talked about the repulsion they had with managing the faeces and incontinence, and their methods of coping by using aids such as masks and gloves to protect them from the faeces and its odour.

*At the beginning I didn't provide masks because I thought I could bear it as she is my mom. But then, if the faeces come out in large amounts, I feel fed up and want to vomit. I do need to be wearing a mask (Dewi).*

Ayu, who took care of her grandmother, wore gloves due to her disgust in touching the faeces and preferred this to washing her hands. Gloves helped her to care for her grandmother:

*At first, I felt disgust of the faeces, but mom told me to endure. Over time, I can cope with the dirt for I wear gloves to clean my grandmother's faeces (Ayu).*

Another participant, who was a neighbour who cared for an older person with faecal incontinence, did not wear gloves or a mask, but always wore different clothes when giving care, so that people would not smell the faeces on her clothes.

*After I take care of her, I always replace my clothes. I always wear different clothes for taking care of her and for other activities. And my clothes will be washed with detergent and dab soap (Misni).*

Among the study participants, there were some family caregivers who did not use any aids to deal with the repulsion, as Titut explained:

*At the beginning, I wore gloves for I felt disgusted, but now, I no longer wear gloves as it takes time. I get used to this disgusting task ... The purpose is to keep my mother from touching the faeces, so I prefer doing it (i.e. cleaning her) as quickly as possible ... At first I did want to vomit, and then I wore a mask. Over time I get used to it. Previously we prepared masks, but lately it is no longer used (laughing) (Titut).*

Each of the participants coped with the disgust they felt in different ways with some adapting or getting used to what was needed to manage faecal incontinence. From this theme, aids such as masks and gloves were enablers for the participants in adapting to the disgusting work.

Taking care of older people who cannot control their defecation is considered quite ordinary in Indonesia. The community accepts that, in general, their functions are in the process of gradual decline. Nevertheless, this cultural fact has brought the family caregivers to an inevitable situation of having to sacrifice their own lives without complaint.

Normally, each house has its own toilet which would have a septic tank to directly collect the faeces from the toilets. Even though automatic flushing toilets are available in Indonesia, the majority of participants do not have this type of toilet. Many of the participants' toilets were flushed manually by pouring in water with buckets. Consequently, the participants would see the faeces before it was flushed away.

#### **4.3.3 A lack of information and education about faecal incontinence**

In faecal incontinence management among older people who need assistance, the basic knowledge and skills of the caregiver are considered to be very important. With only limited sources of faecal incontinence information having been translated into the Indonesian language, it is difficult for participants to find information to care for their family members. Having



insufficient information about care for people with faecal incontinence may impede their performance.

### ***Information-seeking***

Based on the experiences of some of the family caregivers in this study, it was difficult to find information about faecal incontinence, or about caring for older people, through the internet or television, as Siti stated:

*I often watch the TV program from one of the TV station, called Dr Ozy. They have various topics, but never about older people (Siti).*

Information about faecal incontinence in the Indonesian language was also difficult to obtain through the internet. Ayu, a 19 year old girl, had tried and failed to obtain any information through the internet. As she did not have a health education background, or good English language skills, she did not have any idea about how to find the relevant information.

*I've tried to search through the internet, but I didn't get information that I wanted ... I used words "overcoming inability to control defecation" (in Indonesian language). Nothing, it's difficult ... (Ayu).*

Regardless of the electronic medium accessed by people in general, Dewi was an exception in seeking more direct help. She preferred to learn directly from others, rather than to search for information on the internet, so she would ask her neighbours, who were paid carers.

*I don't use the internet as I prefer to learn directly. I more trust in direct learning. My next door neighbour used to hire paid caregivers for looking after her older mother. I used to ask the paid caregivers about how to take care of older people (Dewi).*

Another participant, who was the daughter-in-law of the person with faecal incontinence, had never tried to find information about caring for her relative and preferred to learn through her own experiences.

*Nobody taught me. I only follow the flow; I come to know by myself. It's probably because I have a grandchild aged 3 years who always wears diapers (Juleha).*

This theme demonstrated that most participants tried to search information about faecal incontinence through the internet or television; however, they failed to find information through these media. This lack of information about faecal incontinence in the Indonesian language impedes the care provision of older people with faecal incontinence. The lack of availability of information about faecal incontinence could be because defecation is a natural function of every human being, and people assume that incontinence is normal for older people, and it is even normal for family to care for their older family members who have faecal incontinence. Nevertheless, the carers need to be informed.

#### ***Caregiver's educational needs***

Although information was difficult to find, some caregivers admitted that they needed information and education about faecal incontinence to guide them in caring for their family member in the best possible way. Some other participants mentioned the information that they perceived they needed, as shown below:

*I hope I can get information about how to care for people who have a problem like this, so I will not do the wrong things. A Leaflet is good (Ayu).*

*I need the information about how to care for my mother ... I also need the information about diet management, which food is allowed or not (Dina).*

*I need to know about how to clean the older person who is paralysed. I know how to clean, but cleaning the older person who is paralysed on one side of the body is difficult (Siti).*

This sub-theme confirmed that the caregivers needed verbal and written information in their own language, and in a format that can easily be kept and

referred to, such as a leaflet. The needed information was centred on practical issues such as diet management and how to help with the activities of daily living for the older person.

Hospitals often provide leaflets about specific diseases and their management. However, based on the interviews, it is clear that there are no leaflets available for faecal incontinence management. The leaflets that are available are generally about life-threatening diseases. Moreover, the Indonesian government does not provide any information about faecal incontinence management on their website, as they are more concerned about transmissible diseases such as dengue fever, malaria, influenza, and other life-threatening diseases. It is understandable that in a tropical country, Indonesia has various transmissible diseases which take priority for the government.

#### **4.3.4 A lack of healthcare services for home-dwelling older people with faecal incontinence**

Healthcare services play an important role in health promotion and maintaining people in the community. The healthcare service role is necessary to have a positive impact on the curative and preventive domains in health. Besides private clinics and/or hospitals, there are healthcare providers such as the Puskesmas and the Posyandu Lansia, which are initiated by the government. These two services are well recognized in the community. However, concerns arose around the services in regards to the attention received in, and access to, healthcare services.

##### ***Health care facility services attention***

The participants stated that the health services did not provide the expertise and information or help that they needed to care for a person with

faecal incontinence. The caregivers believed that health professionals gave more attention to treatments rather than to the care required for faecal incontinence. As Dewi, a study participant who is also a volunteer in the integrated healthcare post, stated:

*I didn't get any information of how to care at home. They usually focus on drugs. The health professionals usually show more concern about diseases than about the caring activities (Dewi).*

This finding points to a need for information about taking care of older family member in relation to the day-to-day care practices, rather than the medications or knowledge about diseases.

The health services employ health professionals with different areas of expertise, such as nurses and doctors. Doctors place greater attention on curing, while nurses give more attention to caring. However, as inexperienced people, the caregivers need both of these areas of knowledge. If the health professionals only focus on the curative processes, they fail to meet the needs of people in the communities. In contrast, how affordable the health services are, is also essential.

### ***Health services access***

There are some private and government-run health services available in the community. The participants in this study stated that they deliberately did not use some health services, such as the Posyandu Lansia and the Puskesmas for a range of reasons. Siti explained why she did not use the healthcare service available to her father:

*I know there is an integrated healthcare service post for the older people in this area, but the problem is nobody can help me to bring my father there. Actually, this post also provides a doctor, but it is troublesome to bring my father there (Siti).*

The above statement from Siti that demonstrated her difficulties in accessing the service was also supported by other participants. Not only did the participants view this available service as important, but visits to the home would also be beneficial.

*I need the health professionals not only to come to Posyandu (integrated health post), but also to touch the people directly in their house. So they can know that the community need doctors and nurses to teach them about health (Dewi).*

*I did not know that the nurses can deliver their services at home like home health nurses. When I read the brochure about home health nurses I knew that the service is also for people in general, not only people who had been hospitalised before (Rina).*

Even though Rina needed to pay some money for the service, she felt that this was fine, as long as the nurses could come to the house.

The experiences of Siti, Dewi, and Rina demonstrate a need for flexible healthcare services for older people in the community, especially if faecal incontinence was involved. The frail condition of older people often made it difficult for the participants, and those they care for, to access the services. Instead of bringing their older family members to the facilities, the caregivers preferred to be visited in the home by health professionals such as doctors and nurses, at least on some occasions.

The Indonesian government has introduced an integrated healthcare service post for older people in the community. The Puskesmas attempts to distribute healthcare services so that every person, including home-dwelling older people, get equal opportunity to the health services. Hence, the Posyandu Lansia program was established. The Posyandu Lansia are located close to the communities, so that people can access the services easily. In fact, these community-based facilities are not used by some people in the community, even though the service is free of charge. The problem is not one of transportation,

but instead, it is because the participants think that it is tedious to bring their frail older family member who they have to carry to the facilities. Further, even though the government has provided facilities close to the houses, the landscape in which some of the participants live can only be accessed by motorcycle. Therefore, it is impossible for them to carry their frail family member with a motorcycle, unless they use a wheelchair. In fact, none of the participants have wheelchairs.

#### **4.3.5 Support for caregivers**

It has been previously described in this thesis that there was a lack of information about faecal incontinence as well as healthcare services for caregivers. Meanwhile, it was also obvious that carers needed sufficient support to conduct their tasks. In the interviews, the participants discussed the support they received as primary caregivers. These forms of support are mainly provided by other family members. Very few families used paid caregivers to assist the primary caregivers.

##### ***Support for caregivers by family***

Taking care of older family members with faecal incontinence was considered as not being easy by the participants. The primary family caregivers needed some additional support to care for the person with faecal incontinence. As a family unit, the other members of the family contributed to providing the best care they could. According to the caregivers, the support needed was mostly associated with bathing or showering that usually required more than one person.

*There are always two persons to give a bath to my mother. It's hard for me to bathe her alone so I need another person to help me. I do this in the morning with the paid caregiver. We replace everything (Rina).*

The family caregivers not only needed someone to help during their caring activities but, in some situations, they also needed financial support from other family members. As Budi stated:

*I do my best not to give any burden to my children because I know that they have their own responsibilities. I don't ask them to contribute for monthly expenses ... There are some times when I don't have enough money, in that case I will ask my daughter to help me (Budi).*

Sharing the care with other family members enabled the primary caregivers to provide better care to the care-recipients. These tasks are not easy as the carers need to give up their own time and energy. Getting material support from other family members is helpful, but caregivers also need a companion to meet the care recipients' personal care needs on a daily basis.

### ***Support from paid caregivers***

In Indonesia, there is an option to pay for caregivers to come to the home to support the family if needed and if it is cost-effective. Budi, the 82 year old husband, was no longer able to take care of his wife by himself as she required total assistance. Despite the barriers that impeded him in taking care of his wife, he explored the possible resources he had to provide the best care for his wife, and was able to hire two paid caregivers to support his care.

*I cannot take care of my wife directly. I'm sorry, I can't. It's not because I don't want to, but because I can't. It's beyond my capacity. I do realise that hiring two paid-caregivers cost a lot of money ... They will take turns caring for my wife over a 24 hour period (Budi).*

Employing a paid-caregiver created an economic burden for some of the participants. Dina, an educator, cannot afford to employ a paid caregiver:

*If I am at home, I can take care of my mother by myself. But because I work, there is no choice, I need help to take care of mom ... But again, it's difficult to employ a paid caregiver as they ask for high salary (laughing) (Dina).*

When other family members were no longer able to take care of the family member with faecal incontinence, regardless of their physical barriers or time constraints, a paid caregiver was an option for continuing care provision, if it was affordable.

In the past, most women in Indonesia were housewives who would take care of the family. Nowadays, because of economic factors and because many women are well-educated, this has changed. Women are more likely to contribute financially to the family. Having family and a job adds to their burden, and even more so if they care for their older parents who need assistance with defecating and hygiene. Thus, the caring tasks have a strong influence on family dynamics.

### ***Family dynamics***

Assisting a family member with faecal incontinence for a short period of time did not generally create problems for a family, according to the participants, especially if the care was shared. However, if the caring activities lasted for long periods of time, the family faced significant problems, especially if the caring burden was only carried by the primary caregiver. This study found that family dynamics was an issue that arose from the caring activities. Some families shared the caring duties among family members, as was experienced by Siti:

*We take care of my father in turn. He had stayed with my sisters for some years. At that time, his condition was better than this. He could walk to the bathroom and ate by himself. This is my turn to take care of him (laughing) (Siti).*

Even though the family had taken turns in providing care, Siti found herself more burdened now that it was her turn, because of her father's increasing deterioration and greater needs with increasing faecal incontinence.



On the other hand, Dina and her sister-in-law adjusted their schedule to fit in with each day's activities to look after her mother.

*I don't pay any caregiver to help me take care of my mom. My sister-in-law does it for me when I am at work, from morning up to afternoon (Dina).*

This was different to the situation faced by Dewi, even though her family contributed in other ways.

*My family trust me to take care of our mother. They [other family members] do not care enough to take care of older people; it's true, not many people are willing to take care of older people. So they usually provide the material such as diapers, fruit, and her foods (Dewi).*

Conflicts were sometimes faced by the primary caregivers in this study when they did not have the same ideas as other family members about how to take care of the person with faecal incontinence. Juleha, a daughter-in-law, shared her experience in dealing with a relative.

*My mother-in-law's granddaughter usually comes every day to my house. Sometimes when she thinks that the cloth nappies and clothes that I wash are not clean enough she will wash them again ... My work is not good according to her. I have washed the clothes and hung them on the line; she took them from the line and washed them again. I have told her that I've washed them with soap, I use brush, and I also gave perfume, she still didn't believe in what I did ... So that I don't wash my mother-in-law's clothes anymore, except if she doesn't come in two days (Juleha).*

Juleha experienced a psychological burden when other relatives made comments about the care she gave to the person with faecal incontinence. Other married caregivers also experienced conflict; for example, between a role as a wife for her husband and a role as a caregiver for her own mother. In Moslem belief, a wife must first obey her husband. After the husband, the next person to be respected is the mother. Rina was her mother's only child. She was caught in the dilemma of respecting her husband, but she also felt that she could not ignore her mother, as culturally, a daughter should take care of her older parents, as she pointed out:

*Previously, I brought my mother to live with my family. Then, my mother had told me that she wanted to die in her own house. For me, it's very sensitive thing to ignore. I don't know how to do it, I feel uncomfortable because of that statement ... As the health condition of my mother goes down and down, my husband understood about the situation ... In getting permission from my husband, I've been through some conflicts because of my decision to give full attention for her (eyes glazed) (Rina).*

According to the participants, there were differences in their caring roles and duties to the family, depending on whether they were married or single. As such, a single person who lived with the older parent sometimes found it difficult to refuse the role as a primary caregiver. They chose to take on the responsibility, rather than to create conflict with the married family members. Tika, a single caregiver, shared her experiences about sharing responsibility with her married brother, in the following excerpt:

*Because my parents only have two children and my brother has got married, I think there should be someone who is willing to care for mother. That's what I think ... I cannot say no for looking after my mother ... This is understandable, he has just started his new family, many things that he needs to think of. It's fine with me. It's all up to him, if he remembers my mother, he can give mom a little attention, but he doesn't remember that's all right. I don't want to think too much about this ... These recent months, my brother always gives money regularly. Don't know why, maybe because he feels guilty that he cannot come to visit my mother every day or every week (Tika).*

The caring activities themselves already created significant burdens for the primary caregivers, but when there was conflict within the family or their support system, it was felt more strongly. This burden became heavier if the dynamic processes in the family were not going well or if there were disagreements about the care. Attempts to apply religious doctrine, or their status in the family, were the main factors contributing to conflict in the family. In contrast, Tika, a single Moslem woman, was culturally and religiously obligated to be the caregiver in the family. It is true that coming from a Moslem family, she and her brother were obliged to care for their older parents, but as a

single woman, Tika was more socio-culturally available for this caring task. The next section describes the motivations that enabled caregivers to endure their difficult tasks.

#### **4.3.6 Caregiver's motivations**

Participants also discussed why they made sacrifices to be the primary caregiver for family members with faecal incontinence, and to bear the burden of care. They constantly mentioned their responsibility/duty, filial piety led by female family members, and spirituality from religious beliefs, as strong motivations. These motivations were strongly influenced by Indonesian culture, as will be discussed in the following sections.

##### ***Responsibility/Duty***

The participants all felt a responsibility to care for the person with faecal incontinence, whether as a child or a spouse. This fact is reflected in Dewi's statement:

*First reason why I take care of my mother at home is because I am her daughter. Secondly, it is considered more efficient ... I just think this is strange that our own parent is being cared for by others while her children are busy, so that other people take that responsibility. I don't want it. I want it that in this time I devote myself to take care of my older parent. I take care of my older parent by myself (Dewi).*

Tika, as a daughter, thinks that the responsibility to look after her older mother was a chance to pay back what her mother had done for her in the past, and that it was also her responsibility:

*Because my mother took care of me when I was a child, it might be longer than what I am doing now, as maybe it will only be one, two, or six months long, why I'm complaining? But if it will take a longer time, it's alright ... It's the right time for me to take care of my mother for I don't know if I can have another moment. Anyway, I am her daughter (Tika).*

Misni, the sixty year-old woman who looked after her older neighbour, has her own reasons for sacrificing herself as the caregiver for her older neighbour who had faecal incontinence and dementia, whereby she saw that she had a social responsibility and wanted to be an example for her children.

*I take the responsibility of caring for her because I think it is good when my children see me doing this. Later, they can treat their parents and their parents-in-law the same as what I do now. I do this as an example for them. They should not neglect and ignore the frail older people. It's not good when people see them do that (Misni).*

All the participants stated that it was their duty or responsibility to look after the person with faecal incontinence, regardless of other circumstances. The Indonesian culture of looking after older parents drove some family caregivers to take on caring activities as their responsibility. There are far fewer nursing homes in Indonesia than in some developed countries, such as Australia, with well-developed residential aged care. In Indonesia, the culture, in general, is that older parents are cared by their own children. However, problems may arise in circumstances where the individual who gives care cannot accept the responsibility wholeheartedly.

### ***Filial piety led by female caregivers***

Being part of a family line was not the only factor in deciding who was to be the primary caregiver for a person with faecal incontinence. The other main factor impacting on this was that the care of older people is seen as the primary responsibility of females.

*It's me only who is available to give care because the two other children live far from here (laughing). Yes I have another sibling here, but he is male (Dina).*

Dina's statement highlighted that her gender automatically placed her in the role of primary caregiver for her older parent. Undertaking care activities for her older mother, Dewi was also motivated by her status as a daughter.

*The thing is, I have seen people doing this. And I think, if we do this heart fully, the difficulty factors will disappear. It seems to me like I then can enjoy my duty. So, this is my responsibility as a daughter ... The children will share the expenses but not for taking care of my mother directly. Because my mother has only two daughters, the rest are sons. We know that a male is considered not capable of doing caring things (Dewi).*

In terms of looking after older people, Tika also offered the following opinion of the male gender:

*I think a man normally takes the easiest way. If they can pay someone, they will do that without consideration of the older parent's needs (Tika).*

Gender issues placed some females in the caregiver role and this was taken for granted by the majority of the participants in this study of whom the majority were female. It is common-in Indonesian culture that females are expected to do caring duties in a family.

### ***Spirituality-influenced caregiver decisions***

The participants' caring practices were not only influenced by their cultural backgrounds, but also by their spiritual beliefs. This study found that, in general, the participants' beliefs strengthened them for their duties, as Rina and Misni stated in the following excerpts:

*In my belief, one of the ways of entering the heavenly door is by taking care of older parents (Rina).*

*I hold this as my religious service. My saving for here after. I must accept this sincerely (Misni).*

Rina and Misni viewed their caregiving activities as an opportunity for life after death. They believed that they will be rewarded later after they die.

Moreover, spiritual activities and rituals, such as praying, were identified by the participants as helping with their primary caregiver role and with their ability to cope with the situation, when they thought that they could not bear the burden.

*I pray to God, if He really wants her to live longer, I hope she will get well soon. But if not, please take her life so will not bear the sins. Sometimes when I am pissed off, I jump in with inappropriate words. It seems that I'm not sincere, in fact I do everything sincerely (Misni).*

The spirituality of the participants played an important role in strengthening their sense of duty, even though the duty was a burden and not easy to do. Some churches have a program for older people and their families, and some provide aged-care facilities. In contrast, this program is not provided in the Mosques. This study captured the need for support for Moslem caregivers by the Mosques to strengthening their capability to care for their older family members, especially when there was an obligation to look after their older parents.

#### **4.4 Summary**

This chapter has presented the findings from the interview data. The findings revealed the core care activities of the caregivers and the meaning they ascribed to the care that they gave. The chapter emphasized six main themes: minimizing the detrimental impact of faecal incontinence on the care recipient, containment options for faecal incontinence, the lack of information and education resources on faecal incontinence care, the lack of healthcare services for home-dwelling older people with faecal incontinence, shared care by family members, and the spiritual needs of caregivers. The findings enrich an understanding of caregivers' enablers and barriers of managing faecal incontinence in the home. It was also found that there were some issues for the caregivers that need to be managed.

The findings highlighted that the management of faecal incontinence in Indonesia needs to be improved, considering that currently, there is no specific attention paid to the problem of faecal incontinence. This study revealed the lack of support for caregivers regarding faecal incontinence, as a result of the perception that faecal incontinence is insignificant and quite “normal” among older people. In terms of support, some of the supports that are useful for the caregiver are: material support, knowledge from health professionals or other media about faecal incontinence in general and continence aids, and spiritual support from religious leaders. It was also found that there is a need to manage and regulate the environment by the government. On the other hand, the lack of information and education has impeded family caregivers from undertaking their care role. As a consequence, the highest quality care may not be achieved. Well-informed caregivers would deliver better care for their older family members as shown by some of the participants in the present study. Hence, an attempt needs to be made to address faecal incontinence management among home-dwelling older people in the community.

The issues identified in the interview data will be further discussed in the next chapter. In addition, the findings have been compared to those from previous studies in the next chapter.

## CHAPTER 5: DISCUSSION

### 5.1 Introduction

In the previous chapter, the six major themes identified in the interview data were interpreted and presented. These included: (1) minimizing the detrimental impact of faecal incontinence on the care recipient; (2) incontinence aids; (3) the lack of information and education about faecal incontinence care; (4) the lack of healthcare services for home-dwelling older people with faecal incontinence; (5) support for caregivers; and (6) caregiver's motivations. The findings of this study highlighted the need for developing care services for community-dwelling older people with faecal incontinence in Indonesia. Moreover, the findings also strongly suggested the need for providing information and education support for caregivers in order to improve their caring practice in the communities in which they live. In addition, the religion- and values-based motivations that have been driving many people's caring actions also need to be maintained.

Using Gadamer's hermeneutics, the researcher was able to interpret the caregivers' experiences and the nature of the care activities taking place in the Indonesian socio-cultural context. The enablers and barriers identified from the caregivers' experiences are crucial for community nurses to understand caregivers' needs, and for services to be developed to meet their needs. Gadamer's hermeneutics was also used as a framework in this discussion chapter in order to gain an historical perspective about the issues identified in this study, and how to deal with these issues in the Indonesian context. The findings are also discussed in relation to other studies in the area. The discussion is organised into four sections: (1) faecal incontinence care services



in community settings; (2) core knowledge and skills required for a caregiver engaging in faecal incontinence care; (3) support mechanisms for caregivers to cope with the stress and burdens; and (4) the need for written resources in the Indonesian-language about faecal incontinence care.

## **5.2. Faecal incontinence care services in community settings**

In this study, it was found that most of the day-to-day care challenges that caregivers faced could be resolved through community care services provided by community nurses. The prevention of faecal incontinence-associated complications, and the appropriate use and disposal of continence aids were areas where they could assist. Even though community health centres, employing mostly nurses, have been established in Indonesia since 1968, the nurses' roles are mainly restricted to providing treatment for patients in the community health centre with a minimal focus on managing chronic conditions for home-dwelling older people and supporting them and their caregivers. Education, training, and coaching for frail older people and their family caregivers by community nurses have not yet been established.

Healthcare provision for home-dwelling older people with faecal incontinence in Indonesia was very much overlooked. In developed countries, faecal incontinence is one of the main reasons for institutionalizing older family members (Brown, SH & Abdelhafiz 2011). However, in Indonesia, the majority of people adhere to the tradition of taking care of their parents in the home (Schröder-Butterfill, Fithry & Dewi 2010). In such a socio-cultural environment, community nurses have a more important role to play in order to improve health and wellbeing for home-dwelling older people with faecal incontinence and their family caregiver(s). Through the Alma Ata Declaration, the concept of Primary Health Care (PHC) was introduced in 1978 in Indonesia.

This concept aimed to establish equity of healthcare service provision. The establishment of the Puskesmas and the Posyandu indicates that Indonesia has implemented the PHC (World Health Organization 2008). Nevertheless, in Indonesia, PHC has stressed health promotion rather than the management of chronic conditions such as faecal incontinence.

The lack of healthcare provision through the Posyandu in the community may be due to the lack of a sufficient number of nurses working in the community. Java Island, where the study was conducted, accommodates 60% of the Indonesian population; consequently, it has a high population density of approximately 951 people per sq. km. (Susilo et al. 2012). Therefore, the nurse-to-population ratio must be set up appropriately to achieve equity of healthcare. Actually, in 2010, Indonesia had two nurses for every 1000 people (The World Bank 2014). This number was lower than some other countries in the region, such as Brunei Darussalam, Singapore, and Malaysia, which had seven, six, and three nurses per 1000 people, respectively. The current number of nurses in the community setting in Indonesia is 105,870 working on the estimation that every Puskesmas has 11 to 12 nurses (Depkes RI 2013b). It is estimated that each Puskesmas covers around 33,000 people (Depkes RI 2013b). This means that one nurse is responsible for 3,000 people. Meanwhile, the ideal nurse-to-population ratio, according to Indonesia Sehat 2010, was 11 to 12 nurses per 1000 people (Ditjen Dikti 2010). It is obvious that the nurse-to-population ratio in the community in Indonesia is very low.

As nurses make up the majority of health professionals in Indonesia (Depkes RI n.d.), they are potentially able to have a significant impact on health development. However, Indonesia needs an adequate nurse-to-population ratio (Reit 2010). The improvement of family caregiver support requires an increase

in the numbers of nurses in the Puskesmas, as supported by one study that highlighted that the nurse's workload determined patient outcomes (Aiken et al. 2011). Therefore, the Indonesian government needs to consider increasing the number of community nurses.

Beside their quantity, the quality of the nurses is also important. A study in Hong Kong (Chau et al. 2009) identified that some health professionals lacked health literacy in regard to the issues of older people, which was the same as nurses in Indonesia (Kadar 2011, cited in Kadar, Francis & Sellick 2013). Gillibrand (2012) pointed out that community nurses play an important role in reducing the adverse effects of faecal incontinence. Nurses with insufficient knowledge and skills leads to a lower quality of care (Kadar 2011, cited in Kadar, Francis & Sellick 2013). In addition, with the situation in Indonesia, community nurses need to be well-educated and trained to deliver culturally- and linguistically-appropriate caregiver support in the community (Hennessy et al. 2006). Thus, nurses are required to have sufficient knowledge in their specialities and have advanced education as a basic qualification.

Education plays an important role in the professional development of nurses for improving the quality of care. In the USA, advanced practice nurses were able to deliver high-quality care to patients (Newhouse et al. 2011). The community care nurse is viewed as a specialist in the global context, and this idea has been adapted for the Indonesian context. The advanced practice nurse contributes much to care service development in the community (Imhof et al. 2012) through assessment, and self-care consultations for community-dwelling older people. In an attempt to meet the needs of community nurses, the University of Indonesia established the Community Nurse Specialist Education Program in 2003 (Universitas Indonesia n.d.). It is believed that the

development of a community nursing specialty will lead to the enhanced development of community care services.

One factor that may be a barrier in providing sufficient numbers of community nursing specialists in the Puskesmas and the Posyandu is government policy. The activities in the Puskesmas are mainly funded by the government. Government policies and investments in community nursing largely determine the care services and the quality of care for home-dwelling older people. Up until recently, only a few nurses who work for the Puskesmas and the Posyandu are community nursing specialists. Therefore, nurse education institutions must make the Indonesian government aware of the importance of community nurse specialists that work in the Puskesmas and the Posyandu. Influencing public health policy is important for enhancing health equity (Xiao 2010). This study supports the idea that the underdevelopment of the nursing workforce in community care settings in Indonesia cannot be solved without links between nursing education policy and health system policy.

This study supports the findings of a previous study that showed that healthcare services are underused by older people in the community (Okehealth 2013). Most caregivers in the present study did not bring their older parents to the Puskesmas or the Posyandu because of immobility and their bed-bound status. Therefore, community nurses are required to deliver services to the clients' house. It is difficult for a family to take their frail older family members to the healthcare service, especially for those who live in Jakarta, where half of the study participants live, as they may be confronted with traffic congestion on the way to the healthcare facilities. However, in Indonesia, community nurses do not provide care in the clients' homes, but in the Puskesmas or the Posyandu. This study could not ascertain the functions of community nurses in helping

caregivers in managing faecal incontinence in the home, as interviews with community nurses were not part of this study. However, this study did reveal caregivers' expectations of community care services that might inform policy-makers and community care organisations of the importance of community nurses' roles and responsibilities when planning for service development for home-dwelling older people with faecal incontinence.

The findings from the present study confirm those in previous studies that undeveloped caregiver support via community health centres led to poor care outcomes for home-dwelling frail older people (Wang et al. 2014). The family caregivers in this study were facing challenges in managing faecal incontinence due to their lack of knowledge, skills, and resources in managing faecal incontinence. The study concluded that healthcare providers in the community Puskesmas and Posyandu Lansia had only a limited impact on improving the wellbeing of home-dwelling older people with faecal incontinence. It can be seen that family caregivers struggled to find ways to prevent the adverse effects of faecal incontinence.

The services and resources needed to support people managing faecal incontinence in the home for incontinence care are considered to be highly complex (Flanagan et al. 2014). In Australia, continence nurse advisors can provide support for people in the community who need advice about their continence problems through a free helpline which is funded by the Department of Health and Ageing (Continence Foundation of Australia 2014). The advice provided is not only about how to diagnose and manage the issue and the treatment options of their incontinence problem, but also about continence aid suppliers. Further, people can come to the Continence Resource Centre in the Independent Living Centre to obtain information about the wide range of

incontinence aids (Department for Communities and Social Inclusion 2014). These types of services are useful for family caregivers in the community. How to achieve this level of support for caregivers in Indonesia is further discussed in the next chapter under the heading of recommendations.

### **5.3. Core knowledge and skills required for caregivers in faecal incontinence care**

The present study confirmed the findings of previous studies that providing care in the home environment by family caregivers is highly challenging, and caregivers need to be prepared with adequate knowledge and skills (Simons 2011). In fact, people in the community were generally lacking in health literacy about faecal incontinence (Patel, Bliss & Savik 2010). The present study found that family caregivers did not have sufficient knowledge and were not formally trained to provide care for people with faecal incontinence, whereas practical nursing skills were needed by them (Bee, Barnes & Luker 2009). This study also pointed out that the family caregivers have not been able to obtain any practical information or basic knowledge about faecal incontinence management. Therefore, it is inevitable that they encountered significant difficulties, as described in Chapter Four.

Selecting continence aids may be the most basic form of knowledge that caregivers need. However, without sufficient knowledge, they will not be able to select suitable aids. The lack of awareness of caregivers in the present study about the importance of the selection of continence aids, made them put this question aside. One study confirmed that some people in the community did not wear continence aids because of their lack of knowledge (Bliss et al. 2011). In fact, continence aids are strongly believed to be useful in prevent pressure ulcers (Barker et al. 2013; Fader et al. 2010). It was also suggested that some of

the information that would be useful for selecting continence aid products would be in relation to the size, shape, and effectiveness (Bliss et al. 2011). Since continence aid products tend to fit the needs of the population in general, Fader et al. (2010) suggested that the design of continence aids needs to be improved. With a better understanding of continence aid selection, adverse events may be prevented.

The under-preparation of informal caregivers may contribute to adverse events such as skin problems. The most common skin problems present among people with faecal incontinence are pressure ulcers (Chacon et al. 2009; Park & Kim 2014; Wilczweski et al. 2012) and IAD (Nix & Haugen 2010). These problems are common among dependent older people who have faecal incontinence (Kottner et al. 2014). The prevalence of IAD was in a range between 5.6% and 50% (Beeckman et al. 2009), while the percentage found in two studies showed a prevalence of 70% up to almost 90% for people with pressure ulcers who had an incontinence problem, such as urinary or faecal incontinence (Jenkins & O'Neal 2010; Wilczweski et al. 2012). This data reflects that faecal incontinence affects the skin significantly. Nevertheless, the majority of the caregivers in this study did not show concern about the care recipients' skin problems; only two out of ten caregivers applied a special skin treatment such as coconut oil for frail older people. More investigation about the effectiveness of coconut oil in preventing skin breakdown is needed; however, Bardsley (2013) identified that permeability and hydration, as well as skin repair, can be maintained through applying emollient substances which are rich in lipids and oils. In addition, the lack of concern about skin care from caregivers showed that continence-associated dermatitis was not one of their concerns when caring for older family member with faecal incontinence. Well-

prepared caregivers can prevent the occurrence of adverse developments such as skin damage (Ostwald et al. 2013) which would stop further unneeded expenditure and discomfort (Carey & Stefos 2011).

Faecal incontinence is also a cause of infection because of the damage to skin integrity and cross-contamination (García et al. 2013). Skin infection, and even sepsis, can occur in the care recipient. Caregivers can transfer bacteria from the faeces to the care recipients, other family members, and the environment. One issue that needs to be taken into consideration is related to older people being infected by Methicillin-Resistant Staphylococcus Aureus (MRSA) (García et al. 2013). The caregivers need to ensure that the care activities they undertake are compliant with infection control standards. In the present study, the majority of caregivers did not wear gloves during the cleaning of the faeces. This is contrary to the findings of the previous study which showed a preference for using gloves to protect the caregivers from the faeces (Al-Samarrai et al. 2007). Careful protection should be applied as the carers also need to prepare meals and also feed the older people. One study revealed that 35.6% of older people were hospitalized due to bacterial infections (Zorman et al. 2013). Community nurses have much to do to support family caregivers in developing knowledge and skills in infection control. Recommendations on this area are presented in Chapter Six.

Diet management is another way to address faecal incontinence in the community (Croswell, Bliss & Savik 2010; Peden-McAlpine, Bliss & Hill 2008; Zorman et al. 2013). These studies supported the findings of this study in which some caregivers stated that they need information about foods that are safe for digestion. The caregivers' prior knowledge was not enough to support them in appropriate diet management. In fact, mindful and comprehensive assessments



available to the care recipients, including a bowel diary and the recording of faecal incontinence severity, is paramount (Van Koughnett & Wexner 2013).

While bathing was believed to be an effective way to maintain dignity, caregivers were also concerned about safety in very poor environments with limited resources for bathing care recipients. Stevens, Mahoney & Ehrenreich (2014) highlighted that a bathroom is a common place for falls. The potential issue of having a fall discovered in this study is relevant to the construction of the facilities in the bathroom. Suyasa (2013) stated that in order to facilitate the best bowel evacuation, a squatting toilet is better than a sitting one. However, for older people who have arthritis, a squatting toilet could be a risk factor for having a fall. As Letts et al. (2010) pointed out, squatting may upset one's balance and diminish the strength of the lower extremities. All of the participants had wet floor bathrooms without safety facilities for older people, such as a bath chair or grab rails. Because the majority of the older people were frail, their caregivers and the older people both had the potential to fall while moving to, or being in, the bathroom. A prudent assessment of the safety of the home circumstances for community-living older people is paramount.

Caregivers with insufficient skills in conducting care activities may endanger themselves. In this study, as most of the care recipients were bedridden, the caregivers cleaned them on the bed. Nevertheless, cleaning on the bed was not simple. The caregivers needed help to turn the care recipients' body from side-to-side for complete hygiene. If the bed was not adjustable, for example in its height, caregivers would have to bend down, which may not keep to the normal body alignment, so that a back injury might occur. Persistent kneeling, squatting, and lifting would also lead to lower-back pain (Coenen et al. 2013; Steffens et al. 2014; Sterud & Tynes 2013). The low level of

knowledge about physical stress is also a predicting factor for lower-back pain (Steffens et al. 2014). This point is undebatable - that bathing frail family members, if not undertaken properly, has destructive effects for caregivers. Therefore, the caregivers need to be well-educated about the safety of conducting nursing activities for their older family members.

The absence of good waste disposal management and regulations has a significant impact on the acceleration of environmental destruction. Air pollution is the leading cause of respiratory diseases and allergies (Kelly & Fussell 2011). On the other hand, approximately 80% of people across the planet are threatened by water security issues; yet, global investments for the environment are very few (Vörösmarty et al. 2010). However, one company in Australia (Relivit n.d.) has committed to producing eco-friendly pads that can be recycled. In contrast, this study revealed that the two most common ways of disposing of faecal incontinence undertaken by caregivers were throwing the used diapers into the river or burning them. The caregivers were aware that their behaviour harmed the environment and they felt ashamed to do so. As a result, some of them disposed of the waste early in the morning, or away from their homes. Education and stricter government regulation would lead to a significant impact on the community.

Given that faecal incontinence may lead to devastating impacts for care recipients, caregivers, and the environment, information relating to faecal incontinence management needs to be widely shared throughout the community. It is crucial to ensure that caregivers are equipped with sufficient knowledge. Some of the important knowledge they need are in relation to the selection of continence aids, infection control, diet management, used incontinence aid disposal management, prevention and management of adverse events, and safety

in delivering care such as the right body alignment while undertaking care activities.

#### **5.4. Support mechanisms for caregivers to cope with stress and burdens**

This study confirmed, in line with previous studies, that family caregivers experienced significant care burdens (Osse et al. 2006). The types of care burden found in this study were time, social, financial, physical, and psychological burdens, which are supported by the findings of previous studies (Butler et al. 2005; Cassells & Watt 2003; Drennan et al. 2012; Garcés et al. 2009; Haley et al. 2009; Holdsworth 2013; Tang, Li & Liao 2007). Thrush & Hyder (2014) argued that due to giving high quality care, caregivers in low- and middle-income countries need holistic support. The caregivers need support in order to relieve them from the burdens resulting from heavy care activities that profoundly affected their well-being.

There are many ways to relieve this caregiver burden; for example, using formal support such as community aged-care services and respite care (Short-Term Care Place) (Berglund & Johansson 2013; Orpin et al. 2014), or informal social support through family and friends (Berglund & Johansson 2013; Friedemann-Sánchez 2012; Schröder-Butterfill, Fithry & Dewi 2010; Thrush & Hyder 2014). In the Indonesian socio-cultural context, family support is the main support expected for the care of older parents. Previous studies about informal caregivers of palliative care patients pointed out that respite and the provision of psychological support, such as educating caregivers about coping mechanisms, could be a good option in address their stress (Harding et al. 2011). Although people in Indonesia are not familiar with the concept of “respite” as a formal short-term care venue in which to place older people, some people undertake actions that are similar to the concept of respite. One of the

study participants explained that she and her siblings take their older parents to their homes in turn. On the other hand, some participants shared their turn for care based on their availability over each day. This study finding is in line with a study conducted in rural areas that family caregivers preferred to use support from informal resources such as family and friends (Orpin et al. 2014). Thus, social capital is a potential resource for supporting caregivers and helping them to cope with their caregiving burdens. However, this study did not capture how the caregivers obtain support to improve their coping mechanisms.

Despite the help they received from others, the present study identified that primary caregivers still spent most of their time on caregiving tasks. They were unable to leave the older parents at home without assistance. As a consequence, they lost their own social life. These findings are in line with the findings reported by Cassells & Watt (2003). More strategies to relieve the caregiver burden, for example developing aged-care services in the community care setting via Puskesmas led by community nurses, are necessary. Recommendations on how to relieve caregiver burdens through formal community care services are presented in Chapter six.

The findings from the present study supported a number of previous studies, pointing out that family caregivers experienced a financial burden due to the use of incontinence products and the loss of work hours in their employment (Cassells & Watt 2003; Tang, Li & Liao 2007). Borg & Hallberg (Borg & Hallberg 2006) confirmed that financial and social supports are the most needed forms of support. Financially, family caregivers in this study needed quite significant amounts of money for continence aid provision. One of the study participants admitted that she needed an amount of money for continence aids which was almost equal to the monthly income of another study

participant who could not afford to provide continence aids for her older father. Inevitably, some of them had to quit their job to be able to do their duties. This often caused a double financial problem for the family. In a country without welfare for older people with faecal incontinence, the sharing of the costs of care activities across the family unit is one way to reduce the financial burden. Each family member in this study made their contribution based on their own capacity, including material contributions such as money and continence aids. These findings may be different from studies undertaken in developed countries, with well-established aged-care facilities and welfare for older people (Russell 2013), but they are similar to study findings from other low and middle-income countries with undeveloped aged-care services (Friedemann-Sánchez 2012).

In the present study, the caregivers also received social support from their neighbours when their families lived far away from them. Indonesia has a hand-in-hand culture; besides, Indonesian people hold on to their religious values tightly. For example, Moslem people are commanded to care for others including their neighbours (Quran-Terjemah n.d.). They should not let their neighbours starve and are required to look after poor people. Similarly, Christians are commanded to pass their love on to others, even to their enemies (Biblegateway n.d.). In addition, Hinduism acknowledges the Karma Marga that encourages them to do good things, either for others or for themselves (Bandem n.d.). Moreover, in Indonesian society, it is common for a spontaneous show of help, either material or moral, for friends or neighbours who find themselves in difficulty. It is also common to visit friends, relatives, or neighbours who are sick in hospital or at home. One of the care recipients was taken care of by her neighbour because she did not have a son or daughter. This study revealed that people in the local neighbourhood also have the potential to provide financial as

well as social support. Looking at the religious and cultural values and what has been happening in Indonesia, it is obvious that Indonesia has strong social capital that can be utilized as a support for caregivers.

The management of social capital led by community nurses through collaboration with local government can also enhance support for caregivers. Community-based programs such as the Posyandu Lansia can be a source of support for caregivers as well as for incapacitated older people. Empowering the community to achieve self-reliance in some areas is appropriate for those countries with limited support from the government. The combination of a community-based approach and community facilities would have a positive impact on society (Colbourn et al. 2013) as well as good policy development (Prata et al. 2012). Therefore, mobilizing and organizing the community, and lobbying the local government are considered to be crucial tasks of community nurses.

The findings of this study are also in line with previous studies showing that caregivers' motivations for carrying out their caregiving tasks helped them to endure the burden (Sánchez-Ayéndez 1998). A study by (Quinn et al. 2012) showed that caregivers' motivations determined care outcomes. As religious values dominated these caregivers' motivations, pastoral support from spiritual leaders or colleagues would have a positive impact on the caregivers' quality of life. Support from religious colleagues would have a positive impact on informal caregivers. This finding is supported by a body of evidence in Indonesia and in other countries (Pearce 2005). Within this context, religious organizations such as the local Mosque and churches can contribute to reducing the psychological burden through a spiritual approach, as spiritual support has a

positive impact on a person's health (Krause 2010). Spiritual support for caregivers is therefore crucial.

### **5.5 The need for written resources in the Indonesian language about faecal incontinence care**

The prevalence of faecal incontinence in developing countries is in the range of 5.3% up to 41% (Walker & Gunasekera 2011). More specifically, the prevalence of faecal incontinence among 303 older people in community settings in Bali, Indonesia, is around 22.4% (Suyasa et al. 2014). If the percentage that was found in Bali is applied as a prediction of the number of people with faecal incontinence in Indonesia, it would be projected that the estimated number of older people with faecal incontinence in Indonesia in 2010 would be around 6,309,835 (BPS 2010a). This group of older people should be well cared for in order to prevent faecal incontinence-associated complications, and to improve quality of life.

The level of health literacy of the caregiver will also determine the quality of the care they provide (Lindquist et al. 2011). Nutbeam (2000) pointed out that three types of health literacy empower people to achieve greater capacity and autonomy. These include: functional health literacy, interactive health literacy, and critical health literacy. Functional health literacy relates to cognitive facility, interactive health literacy is achieved when the individual implements their knowledge confidently, and critical health literacy enables the individual to apply their knowledge to the wider context (Nutbeam 2000). It is obvious that in order to deliver high-quality care, the level of caregivers' health literacy needs to be improved and, from the health literacy concept which has been described, it is noted that health education is the starting point of health literacy improvement.

Community nurses play a role as educators in the community. The lack of caregivers' health literacy in this present study can be addressed by providing more and relevant information. Information can be delivered orally or through written resources such as leaflet or booklets. However, it is strongly believed that the caregivers' literacy levels affect their information-seeking ability (Birru et al. 2004). All of the caregivers in this present study have good literacy levels. This is actually a good starting point to get the information out to start improving health literacy. This opinion is supported by studies in some Asian countries which revealed that the higher the educational background, the better people's health status (Chao et al. 2013; Lee et al. 2010). In contrast, high school graduate caregivers would find it difficult to implement healthcare effectively (Centres for Disease Control and Prevention 2009). Thus, caregivers' literacy levels are strongly related to their levels of health literacy. In contrast, Al Qadire (2014) argued that less-educated people would seek information if they thought that they really needed the information. Related to this, community nurses should attempt to make people aware of their needs for information.

Globalization, to some extent, has had a positive impact on the spread of information in that it enables the rapid sharing of information through the internet or television. Information about faecal incontinence across countries can be gained easily using the internet. The ability to use the English language as an international language means that caregivers may obtain useful information about faecal incontinence. However, not all of the caregivers in Indonesia understand English. Language is not the only issue; caring for people with faecal incontinence in the home could also differ depending on one's location. People in the community depend on the features of where they live; for



instance, the culture of their local social environment. People in the community need information which is culturally- and linguistically-appropriate for them to use. Language and cultural aspects can be a barrier to health literacy enhancement (Centres for Disease Control and Prevention 2009). Therefore, it is suggested that the presentation of the information should take into consideration the social and cultural background of the readers.

Recently, Suyasa (2013) attempted to develop a self-care booklet for faecal incontinence that might be acceptable for Indonesian culture. This booklet could be a good resource for the family caregiver and the healthcare volunteer, as it consists of practical information that is useful for people with faecal incontinence and their caregivers. Moreover, this booklet is easy to understand. The booklet includes information about diet and fluid management, the best position for defecation, skin care, continence aids, and the facilities that support faecal incontinence management. Apart from the usefulness of the booklet, it is necessary that people in the community should be informed about the availability of the information relating to faecal incontinence. Washington et al. (2011) stressed that informal caregivers need information which can be easily accessed, is up-to-date, and applicable. Thus, the more accessible resource information is, and the more it is easily updated, the more helpful it will be.

Some of the information required by informal caregivers of people with chronic conditions is the medical issues, service availability, complementary medicine, and home-based care (Washington et al. 2011). The presentation of the information should be understandable to the caregivers (Washington et al. 2011). Therefore, the language, the medical terminology chosen, the appearance, and the pictures should be able to assist the reader to understand the

information. This review (Washington et al. 2011) supports the findings of this study that caregivers need information about caring for their older parents, rather than only about the medicines. Moreover, caregivers with a lot of responsibilities sometimes cannot manage to search for information from healthcare services in their community. In this case, online information delivery would be useful. However, one participant preferred to obtain direct information in the home (from community nurses and people in the community) to online information. In this case, community nurses can play a role as educators as well as acting as advocates for the family caregivers. Regarding the role of information-seeking as one of the important aspects required in the development of health literacy, Ellis et al (2012) suggested that a strong effort by health professionals is needed to ensure that caregivers actively seek health-related information from appropriate and reliable information sources.

The participants in this study were from Jakarta, the capital city of Indonesia, and as well as from the countryside. However, a venue specifically for incontinence problems, such as a continence resource centre, was not found in either of the places where the study was conducted. In Australia, continence resource centres provide many useful services related to incontinence (Department for Communities and Social Inclusion 2014). The absence of this resource in Indonesia may be caused by a lack of awareness of incontinence as a health issue. Again, in Australia, the Continence Foundation of Australia (Continence Foundation of Australia 2014) initiates activities to raise awareness and to educate people in the community about incontinence problems, and this foundation aims to reach all Australians. In the Indonesian context, the Puskesmas and the Posyandu can play a strategic role in empowering people to gain the high level of health literacy that is needed, as pointed out by Taggart et

al. (2012). In addition, a study conducted by Sentell et al. (2014) suggested the allocation of resources in the community by policy-makers to enhance either individual and/or community health literacy.

## **5.6 Summary**

This chapter compared the recent literature with the research findings. It was found that the literature about caregivers of people with faecal incontinence is scarce. Therefore, the researcher has explored this topic about caregivers' experiences from the perspective of other chronic diseases with greater risk of developing faecal incontinence, such as dementia and cancer. The researcher learned that there were many supports, in relation to faecal incontinence among older people, which need to be developed. Some aspects that are urgently needed are accessible information resources that are culturally- and linguistically-appropriate for the Indonesian context, the employment of more community nurses to empower family caregivers and healthcare volunteers for faecal incontinence management, the need for government policy to regulate the environment in regard to waste disposal, as well as the need for religion-based support programs. The next chapter will present the conclusions of the study, which will include the implications, recommendations, and further reflections.

## **CHAPTER 6: CONCLUSION**

### **6.1 Introduction**

In the previous chapter, the main findings were discussed by relating these to the findings from previous studies in the same area. Gadamer's hermeneutics informed the researcher in terms of understanding socially- and culturally-constructed caregiver practice in caring for home-dwelling older people with faecal incontinence in Indonesia. This methodology also enabled the researcher to discuss relevant management strategies reported in the literature that may be adapted to the Indonesian context to address the lack of faecal incontinence care provision. The discussion further facilitated an understanding of what constitutes care for home-dwelling older people with faecal incontinence, and the barriers and enablers of current management.

Some of the factors that would support family caregivers in performing their role were highlighted. The discussion revealed that faecal incontinence management and the resources that need to be developed to support home-dwelling older people with faecal incontinence and their caregivers are important considerations. Although most of the examples of faecal incontinence management and resources were found in developed countries, they may also be applicable in the Indonesian context. This chapter presents a summary of the findings, the implications and limitations of the study, recommendations for future research, and final reflections.

### **6.2 Summary of findings**

This study reported on the experiences of caregivers for home-dwelling older people with faecal incontinence in the Indonesia socio-cultural and historical context. The major themes identified in the interviews included

minimizing the detrimental impacts of faecal incontinence on the care recipients, incontinence aids, the lack of information and education about faecal incontinence care, the lack of healthcare services for home-dwelling older people with faecal incontinence, support for caregivers, and caregiver's motivations. Despite the burden and the complex tasks caregivers experienced, support for them was lacking. Yet, family support had a significant impact on care outcomes. In contrast, this family strength which was based on cultural and religious values had not been utilised as a resource by health professionals in community care settings to improve care outcomes. As well, community care services for home-dwelling older people with faecal incontinence and their caregivers have not been established.

The study participants mainly depended on continence aids, such as disposable pads, as a basic need for people with faecal incontinence. However, information on how to access and select the continence aids was lacking, resulting in a trial and error-based practice. Financial constraints also impacted on the selection of incontinence aids or materials for older people with faecal incontinence. Selection was based primarily on the cost of the products rather than on the needs of the care recipients. Hence, caregivers need to be able to access wide range information about continence aids.

Not only was the provision of incontinence aids an issue, the management of used incontinence aids was also a major environmental issue found in this study. The caregivers performed activities which were potentially harmful to the environment and the community surrounding them, such as burning and throwing used pads into the river. These activities would cause air and water pollution. Their ignorance about safe wastage disposal led them to conduct harmful activities for the community as a whole. It is predicted that they will

continue these detrimental activities if there are no safe government disposal provisions put in place.

Community nurses seem to have not yet contributed to empowering caregivers in their day-to-day practice. One of the reasons may be because of the small number of nurses in the community setting. Community nurses are considered to be the most suitable resources for guiding family caregivers to improve care for older people with faecal incontinence. In this study, the caregivers faced challenges in preventing the care recipients from contracting faecal incontinence-associated complications. However, their need to have information was not supported by relevant sources such as nurses in the community. The lack of support from community nurses is due to the low nurse-to-population ratio in Indonesia.

The present study also showed that the caregivers found it difficult to endure the caregiving tasks. Their spirituality and beliefs played a key role in motivating them to carry out their tasks. However, this study found that support from religious groups was limited.

The quality of care was impeded by the caregivers' health literacy. Although they were willing to be primary caregivers, all of the participants did not have sufficient knowledge about faecal incontinence. The information related to faecal incontinence they expected to get was about diet management and how to clean their older family members who needed to be totally assisted. In fact, the study participants did not receive any information about faecal incontinence in the Indonesian language through either television or the internet.

## **6.3 Recommendations**

This study adds and understanding of how caregivers of community-dwelling older people with faecal incontinence manage care activities, and the factors that affect their practice in the Indonesian context. Providing home-based caring is not easy, especially with restricted healthcare resources and a lack of available information and informal support. The absence of these supports impedes the carers from giving the best care. Based on the research findings, the researcher made a number of recommendations, which are outlined in the following section.

### **6.3.1 Policy development**

- a) Indonesia's government needs to develop a policy that can facilitate community nurses to optimise their professional role to support home-dwelling older people and their family caregivers.
- b) The Puskesmas should include home-care nurse to lead an appropriate program.
- c) The number of nurses allocated in the community should be increased, and it is suggested that they should be community nurses, or at least have a special interest in, and knowledge about, community healthcare so that they can provide care services and supporting mechanisms that are most relevant and effective for older people and their family caregivers.
- d) A firm eco-friendly policy should be established by the local government to prohibit the disposal of continence-aid wastage into the river.
- e) The government needs to support continence-aid producers to design pads from materials that decompose easily, or are eco-friendly in other ways.

- f) The Posyandu for older people can become an effective tool for disseminating information about faecal incontinence to people in the community. The Posyandu can also function as a screening centre in the community. The collaboration among healthcare volunteers in the Posyandu and nurses in the Puskesmas should be developed in order to identify faecal incontinence cases in community-dwelling older people, and referral pathways for cases should be clarified.

### **6.3.2 Healthcare services**

- a) The healthcare services consisting of the Posyandu, the Puskesmas, the public hospitals, and the private hospitals should spread health-related information actively to people in the community.
- b) The private hospitals should have special funding for community services, so that they can also contribute services for poor people who cannot access the health services. This contribution would not necessarily need a great deal of funding, but something simple and significant such as information. The information should be accessible and easy to understand as not all people in the community have good health literacy. The information can be disseminated through leaflets, booklets, radio, television, or on their website.
- c) There is a need to establish a “Continence Resource Centre” in the Puskesmas that covers a large area. A nurse who provides the service must have a strong understanding about incontinence and its management. Through this service, people in the community can obtain information about continence-aids and other relevant information they may need.



### 6.3.3 Nursing practice

- a) The nurses can empower the family caregivers by helping them to develop knowledge and skills on how to look after older people with faecal incontinence in the home, and how to prevent faecal incontinence-associated complications.
- b) Nurses should also pay more attention to identifying faecal incontinence cases in the community, especially among older people, so that the majority of cases can be assisted. The healthcare volunteer in the Posyandu Lansia can be trained in how to recognize faecal incontinence in order to collaborate with healthcare professionals to help people with faecal incontinence and their family caregivers.
- c) Regarding faecal incontinence management, healthcare volunteers in the Posyandu Lansia may be suitable for performing general tasks. They can report faecal incontinence cases to community nurses, motivate family caregivers in their caring roles, and mobilize people to utilize healthcare services as they need.
- d) Nurses and healthcare volunteers in the community can also work in collaboration to educate family caregivers to stop inadequate disposal of continence-aids.
- e) Community nurses need to advocate on behalf of community residents about health environment management, so that the local government can set up a firm policy to maintain a healthy environment.
- f) Nurses will also need to work with religious groups and organizations to enhance support for family caregivers, considering that spirituality and cultural beliefs play a key role in motivating caregivers to care for older people with faecal incontinence.

#### **6.3.4 Nursing education**

- a) Nursing education providers should add a faecal incontinence care topic into the geriatric nursing curriculum, along with urinary continence. The faecal incontinence care topic should emphasize how to recognise cases, the management of faecal incontinence, and how to work with family caregivers to improve home care for older people with faecal incontinence.
- b) Nursing education providers in Indonesia should expand the specialist programs to include continence specialist programs.

#### **6.3.5 Family caregivers**

- a) Primary caregivers should be encouraged to seek help from different sources to enhance their performance and care outcomes, and to reduce the care burden. As a country with a strong family orientation, family members who are not primary caregivers should be given opportunities to attend education programs and counselling, so that they can support the primary caregivers within the family.
- b) Respite for primary caregivers should be available on a regular basis, considering the high levels of care burden placed on them. Practically, family members can make a schedule to share the care tasks with the primary caregivers. Another option may be the use of a paid caregiver to help the primary caregivers in the family.

#### **6.3.6 Community organizations**

- a) Religious groups can also contribute to caregiver support by providing programs to meet the spiritual needs of the caregivers. Support for the families can be undertaken in the home, as a way to provide spiritual support for either the caregivers or the care recipients.

b) Spiritual organizations such as churches or Mosques can create information-sharing programs to help people in the community understand more about their health, especially in relation to the health issues that seem to be common or natural among older people, such as the faecal incontinence problem. Internal resources such as healthcare professionals who are members of these organizations can participate in these activities voluntarily.

### **6.3.7 Implication for future research**

This study has illustrated the caregivers' practice as well as the factors that affect their performance when caring for home-dwelling older people with faecal incontinence in Indonesia. This study has discussed a wide range of caregiving aspects from the family caregiver perspectives. In fact, this study has revealed that there is a lack of support for this group of caregivers in the Community Health Care Centres such as the Posyandu Lansia. Hence, future research is expected to explore the perspectives and experiences of healthcare providers in delivering services to older people with faecal incontinence in the community. It is important to undertake and evaluate intervention programs that develop health literacy about faecal incontinence for people with faecal incontinence and their family caregivers.

In addition, it is important to explore effective approaches to managing faecal incontinence for home-dwelling older people from the perspective of major stakeholders in the community care setting. In addition, the present study has found that two study participants applied coconut oil on the older people's skin. The effectiveness of this traditional herb needs to be further investigated.

A randomized controlled trial would be a suitable methodology to use for investigating the effectiveness of this oil.

#### **6.4 Limitations of the study**

This study has a number of limitations. Firstly, the study cannot be generalized because of the use of a qualitative approach. As a qualitative study, the aim was not to achieve agreement between the experiences of the participants, but rather to gain a better understanding of the experiences of caregivers in a developing country. The findings cannot be used in developed countries, but it is possible that they can be transferred to similar socio-cultural contexts.

As well, because the data was in the Indonesian language, there will be some findings that would be expressed better in the Indonesian language. However, this study was conducted in the researcher's own language, so that the researcher better understands the real meaning of each statement, even though on some occasions, the participants used unusual cultural terminology. In order to lessen the risk of mistranslation, the researcher translated the scripts by herself and then sought opinions from other Indonesian speakers about whether the translations were similar to the real meaning.

Not all of the study participants have the same background. For example, one participant was a care recipient's neighbour, while another was the daughter-in-law of a care recipient. The different backgrounds will have an impact on the caring experiences, particular on their motivations. In order to provide an insight for the purposes of research transferability, the researcher presented the demographic data of the study participants prior to presenting the findings.

## **6.5 Reflections on the research journey**

The researcher is a nurse educator who works in a geriatric department in a nursing school in Indonesia. After conducting this study, the researcher understands that this study will benefit people in the community in general, as well as caregivers for home-dwelling older people with faecal incontinence specifically. This study is the first qualitative study conducted by the researcher. It may have some limitations in the processes of the study. The researcher found that her capabilities in interviewing the study participants were somewhat limited. However, as the first study that has explored caregivers' experiences in managing faecal incontinence among home-dwelling older people in Indonesia, the researcher believes that this study will enrich the research evidence on the area of faecal incontinence.

From the researcher's point of view, Gadamar's hermeneutic circle was very useful in assisting the researcher to gain an understanding of how the socio-spiritual and historical background influenced the present application of faecal incontinence management in Indonesia. Thus, this approach was suitable for addressing the research aim. Moreover, with this approach, the researcher obtained a deep insight into faecal incontinence management that was not merely from the medical aspect, but also from the cultural and spiritual aspects.

## **6.6 Conclusion**

As far as the researcher is concerned, the present study is the first study that has interpreted the experiences of caregivers of home-dwelling older people with faecal incontinence in Indonesia. The study findings confirmed the previous research that caregiving activities result in burdens on caregivers. With a sufficient number of study participants, this first study has presented a comprehensive understanding of how family caregivers provide home-based

faecal incontinence management in Indonesia. With underdeveloped sources, the study participants had experienced higher levels of burden and difficulties in managing faecal incontinence.

The present study found that the participants in this study showed a lower level of health literacy in continence care. This is a strong indicator of the need for an education intervention for caregivers who care for older people with faecal incontinence in Indonesia. Community nurses are in an ideal position to undertake such education interventions to help caregivers to enhance their health literacy about faecal incontinence.

The insufficient support received from the healthcare services in the community, such as the Puskesmas and the Posyandu Lansia was also identified in the study. The limited number of nurses in the community has a negative impact on their capacity to support caregivers. Hence, this research has recommended that policy-makers should consider an increase in staffing levels in the community. In addition, this study has also suggested the optimization of the Posyandu Lansia through its healthcare volunteers. In Indonesia, community health services for home-dwelling older people with faecal incontinence and their caregivers is considerably underdeveloped. There is an urgent need for services to manage chronic health conditions such as faecal incontinence in home-dwelling older people. Thus, the redesign of the scope of services offered by the Posyandu is suggested.

It is considered that Indonesia is a nation with strong culturally-based values that have a significant impact on caregiver motivations. In this study, social capital was found to be a potential resource to support the management of faecal incontinence implementation. Family and neighbours were the main resources for supporting caregivers. In spite of this great social capital in

Indonesia, this resource has not yet been explored or optimized. Thus, the management of social capital was conducted through support from healthcare providers, as well as spiritual organizations, which could be good options for the improvement of faecal incontinence management.

In addition, the present study has captured the environmental issue which arose from the faecal incontinence management practice. The participants' disposal of continence-aids has led to pollution of the environment. This environmental issue will not be fixed without support from policy-makers. Therefore, this study recommends the implementation of some practical ways that can be considered by community nurses and the government to overcome this practice.

## APPENDICES

### Appendix 1 Summary of themes of the literature reviewed

Theme	Reference
<b>Themes 1:</b> The management of faecal incontinence	Bliss & Savik (2008); Bliss Fischer & Savik (2005); Bliss et al. (2011); Croswell, Bliss & Savik (2010); Peden-McAlpine (2008); Bliss & Hill (2008); Al-Samarrai et al. (2007).
<b>Themes 2:</b> Burden experienced by caregivers	Holdsworth (2013); Drennan, Cole & Illffe (2011); Haley et al. (2009); Chong et al. (2014); Finne-Soveri et al. 2007; Sørbye et al (2009); Deljavan (2013); Garcés et al. (2008); Grover et al. (2010); Brown et al. (2009); Cassels & Watt (2003); Butler et al. (2005); Tang, Li & Liao (2007); Sakar & Anand (2013).
<b>Themes 3:</b> Social-cultural-based values of caregiving	Schröder-Butterfill, Fithry & Dewi (2010); Chan & Chui (2011); Sánchez-Ayéndez (2008); Del-Pino-Casado, Frías-Osuna & Moral (2011); Romero-Moreno, Márquez-González, Losada & López (2011); Losada & López (2011).



## Appendix 2 Summary of strengths & weaknesses of the articles

### Summary of strengths

Themes Identified from the Reviewed Studies	Empirical Resources
Use of valid and reliable instrument	Bliss & Savik (2008); Chan & Chui (2011); Haley et al (2009); Del-Pino-Casado, Frías-Osuna & Moral (2011); Finne-Soveri et al (2007); Sørbye et al. (2009); Garcés et al. (2008); Brown et al. (2009); Butler et al (2005); Romero-Moreno, Márquez-González, Losada & López (2011); Chappell (2008).
Good sample size	Finne-Soveri et al (2007); Grover et al (2010); Brown et al (2009); Sørbye et al (2009); Garcés et al (2008); Chong et al. (2014); Bliss, Fischer & Savik (2005).
Representative participants	Bliss & Savik (2008); Chan & Chui (2011); Drennan, Cole & Illiffe (2011); Haye et al. (2009); Del-Pino-Casado, Frías-Osuna & Moral (2011).
Random participant selection	Bliss & Savik (2008); Grover et al. (2009); Chappell (2008).
Randomised controlled trial	Al-Samarrai et al. (2007).
Concern about ethical issue	Al-Samarrai et al. (2007); Cassells & Watt (2003); Chan & Chui (2011); Peden-McAlpine (2008); Bliss & Savik (2008); Tang, Li & Liao (2007); Drennan, Cole & Illiffe (2011); Drennan, Cole & Illiffe (2011); Finne-Soveri et al (2007); Sørbye et al (2009); Romero-Moreno, Márquez-González, Losada & López (2011).
Rigour	Peden-McAlpine (2008); Haley et al. (2009); Deljavan (2013).

### Summary of weaknesses

Themes Identified from the Reviewed Studies	Empirical Resources
Small sample size	Al-Samarrai et al (2007), Bliss & Savik (2008), Bliss et al. (2011); Drennan et al (2011); Haley et al. (2009); Butler et al (2005); Deljavan (2013); Sarkar & Anand (2013).
Non representative participants	Holdsworth (2013); Butler et al (2005); Haley et al. (2009).
Non-standardized instrument	Holdsworth (2013).
Convenient sampling	Cassells & Watt (2003); Chan & Chui (2011); Tang, Li & Liao (2007).
Cross-sectional design	Bliss & Savik (2008), Chan & Cui (2011), Haley et al. (2009), Del-Pino-Casado, Frías-Osuna & Moral (2011); Holdsworth (2013); Tang, Li & Liao (2007).
Secondary data analysis	Del-Pino-Casado, Frías-Osuna & Moral (2011), Croswell et al. (2010); Chong et al. (2014).
Internet-based or methodology	Bliss & Savik (2008).
Phone-based data collection	Butler et al (2005).
Do not mention ethics approval	McAlpine et al (2008), Schröder-Butterfill, Fithry & Dewi (2010); Sarkar & Anand (2013).

### Appendix 3 Summary of literature reviewed

Author and Year	Aims/ Objectives	Sample and Setting	Methods, Methodology and Level of evidence	Major findings	Strength/ Limitation	Significance to the issue
Peden-McAlpine, Bliss & Hill (2008)	Exploring the experience of women living with Faecal Incontinence (FI) from their perspective and to elicit women's self-care and management strategies for FI.	<ul style="list-style-type: none"> <li>- 10 females with faecal incontinence, (aged 35 to 78 years)</li> <li>- Mineappolis</li> </ul>	Van Manen's Phenomenological approach	<ul style="list-style-type: none"> <li>- Participants experienced feelings of high anxiety.</li> <li>- The self-care strategies conducted by the participants: determining the location of restroom, diet management, medication, wearing absorbent pad, having routine planning behaviours, limiting travel.</li> <li>- Participants could not implement the best self-care practice due to lack of information from health professionals.</li> </ul>	<ul style="list-style-type: none"> <li>- Strengths: has ethical approval from the University of Minnesota Institutional Review Board and obtained informed consents from participants. Rigour (credibility and dependability, conformability, transferability and auditability) was achieved.</li> </ul>	<ul style="list-style-type: none"> <li>- A feeling of shame impedes care seeking.</li> <li>- The lack of information from health care professionals results in poor self-care.</li> </ul>

Author and Year	Aims/ Objectives	Sample and Setting	Methods, Methodology and Level of evidence	Major findings	Strength/ Limitation	Significance to the issue
Bliss et al. (2011)	Describing the use of disposable absorbent products by community dwelling people with FI.	<ul style="list-style-type: none"> <li>- 189 Community-living older people with faecal incontinence</li> <li>- The United Kingdom</li> </ul>	<ul style="list-style-type: none"> <li>- Survey</li> <li>- Level III</li> </ul>	<ul style="list-style-type: none"> <li>- Absorbent products (45%) were used by community-living persons with higher severity of FI.</li> <li>- On average, they replaced the absorbent products 1-3 times in a day.</li> <li>- A modification of absorbent products was suggested to make it more suitable and convenient.</li> <li>- Some suggestions were: designing the size, shape, material, odour control ability, ability of absorbing the leakage of faeces.</li> <li>- Reasons of not using absorbent products: perception that their FI is not bad (39%), personal preference (13%), discomfort (10%), embarrassment (7%), did not know the product (6%), poor fit (5%), cost (4%), and lack of effectiveness (2%).</li> </ul>	<ul style="list-style-type: none"> <li>- Limitation: small sub-group sizes, responses to survey questions reflect recall rather than daily report.</li> </ul>	The findings give an insight of the importance of absorbent products for community-living people.

## Appendix 4 Ethics approval from SBREC

### FINAL APPROVAL NOTICE

Project No.:	6258		
Project Title:	The caregiver's experiences of caring community-dwelling older people with faecal incontinence		
Principal Researcher:	Ms Ernawati		
Email:	<a href="mailto:erna0004@flinders.edu.au">erna0004@flinders.edu.au</a>		
Address:	School of Nursing and Midwifery		
Approval Date:	3 October 2013	Ethics Approval Expiry Date:	31 August 2014

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment:

#### Additional information required following commencement of research:

1. Please ensure that copies of the correspondence granting permission to conduct the research from all hospitals are submitted to the Committee *on receipt*. Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 2).

### RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

#### 1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au).*

#### 2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **3 October** (approval anniversary date) for the duration of the ethics approval using the annual / final report pro forma available from [Annual / Final Reports](#) SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

### 3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a [Modification Request Form](#) to the [Executive Officer](#). Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

#### Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

### 4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or [human\\_researchethics@flinders.edu.au](mailto:human_researchethics@flinders.edu.au) immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that affects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Mikaila Crotty

Ethics Officer and Joint Executive Officer

Social and Behavioural Research Ethics Committee

c.c. Ms Lily X  
Dr Anita De Bellis

[Mrs Andrea Fiegert and Ms Mikaila Crotty](#)

Ethics Officers and Joint Executive Officers, Social and Behavioural Research Ethics Committee

Telephone: +61 8 8201-3116 | Andrea Fiegert (Monday – Wednesday)

Telephone: +61 8 8201-7938 | Mikaila Crotty (Wednesday – Friday)

Web: [Social and Behavioural Research Ethics Committee](#)

Manager, Research Ethics and Integrity – Dr Peter Wigley

Telephone: +61 8 8201-5466 | email: [peter.wigley@flinders.edu.au](mailto:peter.wigley@flinders.edu.au)

Research Services Office | Union Building Basement

Flinders University

Sturt Road, Bedford Park | South Australia | 5042

GPO Box 2100 | Adelaide SA 5001

Appendix 5 Letter of approval from Sint Carolus Hospital (Indonesian Language)



PELAYANAN KESEHATAN **St. Carolus**

Jl. Salemba Raya No. 41  
JAKARTA - INDONESIA 10440  
Telp. 3904441

Jakarta, 1 November 2013

No. : 623/SI-STIKSC/XI/2013/DIRUT  
Perihal : **Permohonan Ijin Penelitian**

Kepada Yth.:  
**Ibu Asnet Leo Bunga**  
K e t u a  
STIK Sint Carolus

Dengan hormat,

Sehubungan dengan surat Ibu No. 463/P.Penelitian/STIKSC/IX/2013 perihal seperti tersebut diatas, dengan ini kami sampaikan bahwa kami memberikan ijin kepada seorang Staf Pengajar STIK Sint Carolus : Ernawati, SKp – No.Pegawai : 144 untuk melakukan penelitian di P.K. St. Carolus.

Untuk teknis pelaksanaannya dapat menghubungi **Ibu Bertha Tri Sumartini, MKep – Ketua Komite Keperawatan.**

Demikian disampaikan, atas perhatian dan kerjasamanya kami ucapkan terima kasih.

Hormat kami,  
Direktur Utama P.K. St. Carolus

**dr. Markus Waseso Suharyono, MARS**

Tembusan :

- Direktur Keperawatan
- Ketua Komite Keperawatan

## Appendix 6 Letter of approval from Sint Carolus Hospital (English)

No. : 623/SI-STIKSC/XI/2013/DIRUT

Subject : Research Permit Application

Dear.:

Mrs. Asnet Leo Bunga

Chairman of Sint Carolus School of Health Sciences

With respect,

Regarding the letter no. 463/P.Penelitian/STIKSC/IX/2013 subject as mentioned above, we hereby inform you that we are giving permission for a faculty of Sint Carolus School of Health Sciences: Ernowati, SKP - No.. Employees: 144 to conduct research in Sint Carolus Hospital.

For technical implementation you can contact Mrs. Bertha Tri Sumartini, MKep. - Chairman of the Committee on Nursing.

This was conveyed, for your attention and cooperation we thank you.

Sincerely,

Director of Sint Carolus Hospital

dr. Mark Waseso Suharyono, MARS

Copy to:

- Director of Nursing
- Chairman of the Committee on Nursing



## Appendix 7 Letter of introduction



**Dr Lily Dongxia Xiao RN MNg PhD  
FRCNA**

Senior lecturer

School of Nursing & Midwifery  
Faculty of Health Sciences  
Flinders University - Adelaide  
South Australia  
GPO Box 2100, Adelaide 5001  
Australia

Ph (61-8) 8201 3419

Fax (61-8) 8276 1602

Dear Sir/Madam,

My name is Lily Dongxia Xiao, a senior lecturer in School of Nursing & Midwifery at Flinders University, South Australia. This letter is to introduce Ms. Ernawati who is a Master student at the School of Nursing and Midwifery at Flinders University. She has included a copy of her student card, which carries a photograph, as proof of identity.

Ernawati is undertaking research leading to the production of a thesis and other publications on the subject of 'The caregiver's experiences of caring for community-dwelling older people with faecal incontinence'. It is hoped that this study will inform the nursing education as well as community health care service providers in Indonesia about the challenges that the caregivers face in caring for the older people with faecal incontinence.

To conduct this project Ernawati seeks your permission to do interview to the participants that will be recruited from outpatient unit in your institution. The participants will need to be a family caregiver of older people with faecal incontinence who willing to participate in this study voluntarily. The prospective participants have the right to refuse participating in this study without any consequences.

Ethics approval will be obtained from Flinders University and Southern Adelaide Health Service Social and Behavioural Research Ethics Committee. Pending your letter of approval

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(my email address below) Erna hopes to start data collection in 29 September 2013 through to 31 December 2013. Please do not hesitate to contact me on +61 8 82017641 or email [lily.xiao@flinders.edu.au](mailto:lily.xiao@flinders.edu.au) if you require more information about the proposed research.

Kind Regards

Dr Lily Dongxia Xiao

Dr. Lily Dongxia Xiao RN MNg PhD FRCNA  
Senior Lecturer  
School of Nursing & Midwifery  
Faculty of Health Sciences  
Flinders University  
GPO BOX 2100  
ADELAIDE SA 5001  
AUSTRALIA

Telephone: (+61 8) 8201 3419  
Facsimile: (+61 8) 8276 1602  
Pager: 8273 4166  
E-mail: [lily.xiao@flinders.edu.au](mailto:lily.xiao@flinders.edu.au)  
Website: <http://www.flinders.edu.au/people/lily.xiao>

## Appendix 8 Letter of introduction (Indonesian language)



**Dr Lily Dongxia Xiao RN MNg PhD  
FRCNA**

Dosen Senior

School of Nursing & Midwifery  
Faculty of Health Sciences  
Flinders University - Adelaide  
South Australia  
GPO Box 2100, Adelaide 5001  
Australia

Ph (61-8) 8201 3419

Fax (61-8) 8276 1602

E-mail: [lily.xiao@flinders.edu.au](mailto:lily.xiao@flinders.edu.au)

Yang terhormat Bapak/ Ibu,

Nama saya adalah Lily Dongxia Xiao, dosen senior di Fakultas Keperawatan & Kebidanan Universitas Flinders, Australia Selatan. Dalam surat ini saya memperkenalkan saudari Ernawati sebagai mahasiswa program Master di Fakultas Keperawatan & Kebidanan Universitas Flinders (kartu pelajar terlampir sebagai bukti identitas).

Ernawati sedang melakukan penelitian dalam rangka penyusunan tesis dengan judul "Pengalaman Anggota Keluarga dalam Memberikan Perawatan Kepada Lansia dengan Masalah Fekal Inkontinensia di Rumah". Diharapkan penelitian ini akan berkontribusi dalam memperkaya pengetahuan bagi pendidikan keperawatan dan pemberi pelayanan kesehatan dalam hal perawatan lansia dengan masalah fekal inkontinensia di rumah.

Dalam melakukan penelitian ini, Ernawati membutuhkan ijin Anda untuk merekrut partisipan penelitian melalui unit rawat jalan di institusi Anda. Partisipan yang diharapkan adalah seseorang anggota keluarga yang berperan sebagai pemberi asuhan utama bagi lansia dengan masalah fekal inkontinensia di rumah. Partisipasi bersifat sukarela, calon partisipan memiliki hak untuk tidak berpartisipasi dalam penelitian ini tanpa konsekuensi apapun.

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Persetujuan penelitian telah diberikan oleh Flinders University dan Komite Etik Penelitian Pelayanan Kesehatan Sosial dan Perilaku Adelaide (SBREC) akan memberikan surat ijin meneliti setelah mendapatkan surat ijin penelitian dari institusi anda. Ernawati berharap untuk mulai mengumpulkan data penelitian pada tanggal 23 September 2013 sampai 31 Desember 2013. Silahkan menghubungi saya di nomor +61 8 82017641 atau email [lily.xiao@flinders.edu.au](mailto:lily.xiao@flinders.edu.au) jika anda memerlukan informasi lebih lanjut tentang penelitian ini.

Kind Regards

Dr Lily Dongxia Xiao

## Appendix 9 Information sheet



**Ernawati**  
Postgraduate Student  
School of Nursing & Midwifery  
Faculty of Health Sciences  
Flinders Drive, Bedford Park SA 5042  
GPO Box 2100  
Adelaide SA 5001  
Tel : +61 410 111 954 (Australia)  
+62 81283944341 (Indonesia)  
e-mail: [erna0004@flinders.edu.au](mailto:erna0004@flinders.edu.au)

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### INFORMATION SHEET

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**Title: 'The caregiver's experiences of caring for community-dwelling older people with faecal incontinence'**

**Investigators:**

Ms Ernawati  
School of Nursing & Midwifery  
Flinders University  
Ph: +62 812 8394 4341 (Indonesia)  
+61 410 111 954 (Australia)  
e-mail: [erna0004@flinders.edu.au](mailto:erna0004@flinders.edu.au)  
[ernawaties@yahoo.com](mailto:ernawaties@yahoo.com)

**Description of the study:**

This study is part of the project entitled 'The caregiver's experiences of caring for community-dwelling older people with faecal incontinence'. This project will investigate the experiences of family caregiver through interview. This project is being conducted by Ms Ernawati a Postgraduate Student at School of Nursing & Midwifery at Flinders University, Adelaide, South Australia.

**Purpose of the study:**

This project aims to find out the experiences of the primary family caregivers who caring for their older family member with faecal incontinence with the specific objectives as following:

1. To investigate what constitutes caregiving for older people with faecal incontinence in home-based care.

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2. To investigate what are caregivers' perceptions of enablers and barriers in managing faecal incontinence at home.

**What will I be asked to do?**

You are invited to do a one-on-one interview session with researcher voluntarily. In this interview you will be asked to answer a few questions relating to your experiences as a caregiver. The interview will be held in your house or in the hospital room around 60 to 120 minutes. If before those determined time you want to finish the interview session you can withdraw without any consequences. The interview will be recorded using a digital voice recorder to help with looking at the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and then destroyed once the results have been finalised.

**What benefit will I gain from being involved in this study?**

The sharing of your experiences will enrich the knowledge of how to manage faecal incontinence among older people at home. Furthermore, by identifying factor enablers or barriers to perform your duty you can also contribute to share information of how to improve the quality of life of older people with faecal incontinence that live at home.

**Will I be identifiable by being involved in this study?**

We do not need your name and you will be anonymous. Once the interview has been typed-up and saved as a file, the voice file will then be destroyed. Any identifying information will be removed and the typed-up file stored on a password protected computer that only the investigator (Ms Ernawati) will have access to.

**Are there any risks or discomforts if I am involved?**

You might experience the emotional discomfort as you explain about the challenges of performing your roles as a caregiver, but you can refuse to answer some question if you do not want to answer. If you feel you cannot continue the interview session, you can withdraw any time without any consequences. If after interview session you notice that the interview affects you emotionally, the support services will be provided for you to recover from that that problem.

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the investigator.

**How do I agree to participate?**

Participation is voluntary. If you willing to participate to this study you can fill the response slip and give it back to the person who gives this envelope and you will be contacted later. Otherwise, you can send it to the address given below, or contact the researcher through e-mail or contact number. A consent form will be given to you if you agree to participate, and you need to sign it before starting the interview.

**How will I receive feedback?**

Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

**Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.**

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6258). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)*

## Appendix 10 Information sheet (Indonesian language)



Ernawati  
Mahasiswa Program Master  
School of Nursing & Midwifery  
Faculty of Health Sciences  
Flinders Drive, Bedford Park SA 5042  
GPO Box 2100  
Adelaide SA 5001  
Tel : +61 410 111 954 (Australia)  
+62 81283944341 (Indonesia)  
e-mail: [erna0004@flinders.edu.au](mailto:erna0004@flinders.edu.au)  
[ernawaties@yahoo.com](mailto:ernawaties@yahoo.com)

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### LEMBARAN INFORMASI

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**Title: "Pengalaman Anggota Keluarga dalam Memberikan Perawatan Kepada Lansia dengan Masalah Fekal Inkontinensia di Rumah"**

**Peneliti:** Ernawati, SKp.

**Penjelasan tentang penelitian:**

Judul dari penelitian ini adalah "Pengalaman Anggota Keluarga dalam Memberikan Perawatan Kepada Lansia dengan Masalah Fekal Inkontinensia di Rumah". Penelitian ini akan mengeksplorasi pengalaman dari anggota keluarga yang merawat lansia (usia 60 tahun atau lebih) dengan ketidakmampuan mengontrol buang air besar melalui interview. Penelitian ini akan dilakukan oleh Ernawati, mahasiswi program Master di Jurusan Keperawatan dan Kebidanan di Flinders University, Adelaide, South Australia.

**Tujuan penelitian:**

Penelitian ini bertujuan untuk mengetahui pengalaman dari anggota keluarga yang memberikan asuhan pada lansia dengan ketidakmampuan mengontrol buang air besar, dengan tujuan khusus sebagai berikut:

1. Mengeksplorasi cara perawatan lansia yang tidak mampu mengontrol buang air besar di rumah.
2. Mengeksplorasi persepsi dari pemberi asuhan di dalam keluarga tentang faktor yang mempermudah dan mempersulit dalam merawat anggota keluarga dengan ketidakmampuan mengontrol buang air besar.

**Apa yang diharapkan dari saya dalam penelitian ini?**

Anda diundang untuk berpartisipasi secara sukarela dalam wawancara tatap muka dengan peneliti. Dalam wawancara ini Anda akan diminta untuk menjawab beberapa pertanyaan terkait dengan

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pengalaman Anda sebagai pemberi asuhan kepada anggota keluarga anda yang lansia. Wawancara akan dilaksanakan selama sekitar 60 menit sampai 120 menit di rumah Anda atau di tempat yang nyaman bagi anda. Jika sebelum waktu yang ditetapkan Anda ingin mengakhiri proses wawancara, peneliti akan dengan senang hati memberikan ijin tanpa konsekuensi apapun. Wawancara akan direkam dengan menggunakan perekam dan dituangkan dalam bentuk tulisan. Hasil naskah akan disimpan dalam computer dan akan dimusnahkan saat hasil penelitian didapatkan.

**Manfaat yang saya dapatkan jika berpartisipasi dalam penelitian ini?**

Partisipasi anda dalam penelitian ini mungkin tidak akan memberikan manfaat secara langsung bagi anda. Meskipun demikian, pengalaman yang anda bagikan melalui penelitian ini akan berkontribusi untuk memperkaya pengetahuan tentang perawatan lansia dengan ketidakmampuan mengontrol buang air besar di rumah. Selain itu, dengan memberikan informasi terkait dengan faktor yang mempermudah atau mempersulit tugas anda sebagai pemberi asuhan di rumah, secara tidak langsung akan membantu dalam peningkatan kualitas hidup dari lansia dengan masalah tersebut.

**Apakah saya dapat diidentifikasi jika terlibat dalam penelitian ini?**

Tidak ada informasi yang dapat mengidentifikasi diri anda. Kami tidak memerlukan nama anda dan data yang diperoleh dari anda akan diberikan nama yang bukan sebenarnya. Setelah hasil wawancara ditranskrip dan disimpan sebagai data, rekaman suara akan dihapuskan. Semua data yang dapat diidentifikasi akan dihilangkan dan data akan disimpan dalam perangkat komputer dengan menggunakan kata kunci dan hanya dapat diakses oleh peneliti (Ernawati).

**Apakah ada resiko atau ketidaknyamanan apabila saya terlibat dalam penelitian ini?**

Anda mungkin akan mengalami ketidaknyamanan emosional saat menceritakan tentang pengalaman anda, akan tetapi anda diperkenankan untuk mengentikan proses wawancara jika anda merasakan ketidaknyamanan tersebut tanpa konsekuensi apapun. Jika anda merasakan ketidaknyamanan emosional saat wawancara selesai dilakukan, anda tetap bisa menyampaikan kepada peneliti.

**Bagaimana apabila saya setuju untuk berpartisipasi?**

Partisipasi dalam penelitian ini adalah secara sukarela. Jika anda bersedia berpartisipasi dalam penelitian ini Anda dapat mengisi lembar respon dan mengembalikannya kepada orang yang telah memberikan amplop kepada Anda atau menghubungi peneliti melalui telepon, sms, email, atau

mengirimkan slip respon tersebut via pos. Selanjutnya peneliti akan menghubungi anda dan anda akan mengisi lembar persetujuan sebelum wawancara dilaksanakan.

**Bagaimana saya menerima umpan balik?**

Hasil dari penelitian ini akan dirangkum dan akan diberikan kepada anda oleh peneliti apabila anda ingin mengetahuinya.

**Terima kasih atas waktu Anda membaca lembaran informasi ini, dan kami berharap anda bersedia secara sukarela untuk berpartisipasi dalam penelitian ini.**

Penelitian ini sudah mendapatkan ijin dari Flinders University Social and Behavioural Research Ethics Committee (No Proyek 6258). Keterangan lebih lanjut terkait ijin ini dapat menghubungi Executive Officer of the Committee melalui nomor telepon 8201 3116, atau fax 8201 2035 maupun melalui email [human.researchethics@flinders.edu.au](mailto:human.researchethics@flinders.edu.au)

## Appendix 11 Participation response sheet

### Response Slip Provided by Participants

I have read the information sheet of the study of 'The caregiver's experiences of caring for community-dwelling older people with faecal incontinence'. I would like to participate in the interview, and willing to arrange the date, time and venue of the interview. Here are my contact details:

My name : \_\_\_\_\_  
My title : Mr Mrs Ms Miss (circle one of this)  
My Age : \_\_\_\_\_

The most suitable date and time for me to do the interview are:

1. Date (please tick, can be more than one):

Monday       Tuesday       Wednesday  
 Thursday       Friday       Saturday       Sunday

2. Time (please tick, can be more than one):

Morning, 09:00-13:00  
 Afternoon, 13:00-17:00  
 Evening, 18:00-20:00

My mail address:

\_\_\_\_\_  
\_\_\_\_\_ Post code: \_\_\_\_\_

My e-mail address:

\_\_\_\_\_

My daytime contact number:

\_\_\_\_\_

**Thank you!**

Ernawati  
School Nursing & Midwifery, Flinders University GPO Box 2100 Adelaide SA 5001  
Telephone: (+61) 410 111 954 (Australia); (+62) 812 8394 4341 (Indonesia)  
e-mail: [erna0004@flinders.edu.au](mailto:erna0004@flinders.edu.au) ; [ernawaties@yahoo.com](mailto:ernawaties@yahoo.com)

## Appendix 12 Participation response sheet (Indonesian language)

### Lembar Respon Responden

Saya telah membaca keterangan pada lembaran informasi penelitian tentang 'Pengalaman Anggota Keluarga dalam Memberikan Perawatan Kepada Lansia dengan Masalah Fekal Inkontinensia di Rumah'. Saya bersedia berpartisipasi dalam wawancara, dan bersedia mengatur tanggal dan waktu wawancara. Berikut ini adalah data saya:

Nama : \_\_\_\_\_  
Status :  Menikah                       Belum/tidak menikah                      (Beri tanda )  
Umur : \_\_\_\_\_

Hari dan waktu interview yang saya pilih adalah:

1. Hari (beri tanda , dapat memilih lebih dari satu):

Monday                       Tuesday                       Wednesday  
 Thursday                       Friday                       Saturday                       Sunday

2. Time (beri tanda , dapat memilih lebih dari satu):

Pagi, 09:00-13:00  
 Siang, 13:00-17:00  
 Malam, 18:00-20:00

Alamat:

\_\_\_\_\_  
\_\_\_\_\_  
Kode pos: \_\_\_\_\_

Alamat e-mail:

\_\_\_\_\_

Nomor kontak:

\_\_\_\_\_

**Terima Kasih!**

Ernawati  
School Nursing & Midwifery, Flinders University GPO Box 2100 Adelaide SA 5001  
Telephone: (+61) 410 111 954 (Australia); (+62) 812 8394 4341 (Indonesia)  
e-mail: [erna0004@flinders.edu.au](mailto:erna0004@flinders.edu.au) ; [ernawaties@yahoo.com](mailto:ernawaties@yahoo.com)

## Appendix 13 Consent form



### CONSENT FORM FOR PARTICIPATION IN RESEARCH (by semi-structured interview)

The Caregiver's Experiences of Caring for Community-dwelling Older People  
with Faecal Incontinence

I .....

being over the age of 18 years hereby consent to participate as requested in the semi-structured interview for the research project on .....

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio/video recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
  - I may not directly benefit from taking part in this research.
  - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
  - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
  - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
  - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
  - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree/do not agree\* to the tape/transcript\* being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.  
*\* delete as appropriate*
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

**Participant's signature.....Date.....**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's name**.....

**Researcher's signature**.....**Date**.....

*NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.*

8. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

**Participant's signature**.....**Date**.....

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my information as reported.

**Participant's signature**.....

**Appendix 14 Consent form (Indonesian language)**



**LEMBAR PERSETUJUAN PENELITIAN**  
**(Wawancara)**

“Pengalaman Anggota Keluarga dalam Memberikan Perawatan Kepada Lansia dengan Masalah Fekal Inkontinensia di Rumah”

Saya.....

Berusia lebih dari 18 tahun, bersedia berpartisipasi dalam wawancara untuk penelitian pada .....

1. Saya telah membaca informasi yang diberikan.
2. Prosedur dan risiko yang mungkin dihasilkan dari penelitian ini sudah dijelaskan oleh peneliti.
3. Saya bersedia, jika proses interview direkam dengan menggunakan perekam suara.
4. Saya menyadari bahwa saya harus menyimpan salinan dari lembar informasi dan lembar persetujuan untuk kepentingan di waktu mendatang.
5. Saya memahami bahwa:
  - Saya tidak secara langsung mendapatkan manfaat dari penelitian ini.
  - Saya diberikan kebebasan untuk mengundurkan diri dari penelitian ini kapanpun, dan saya memiliki hak untuk tidak menjawab beberapa pertanyaan yang diajukan.
  - Sekiranya hasil penelitian ini dipublikasikan, maka identitas saya akan tetap terjaga kerahasiaannya.
  - Apapun keputusan saya, berpartisipasi atau tidak dalam penelitian ini, tidak akan ada konsekuensi apapun terhadap saya.
  - Saya dapat meminta peneliti untuk berhenti merekam kapanpun saya anggap perlu, dan diperkenankan untuk berhenti dari keterlibatan di dalam penelitian ini tanpa konsekuensi apapun.
6. Saya setuju memberikan ijin kepada pihak di luar peneliti untuk mengakses rekaman suara dengan seijin peneliti, dengan syarat bahwa peneliti akan tetap merahasiakan identitas saya.
7. Saya memiliki kesempatan untuk mendiskusikan dengan anggota keluarga saya yang lain untuk berpartisipasi dalam penelitian ini.

Tanda tangan responden..... Tanggal.....

Saya menyatakan bahwa saya telah menjelaskan tentang penelitian ini kepada responden penelitian, dan menganggap bahwa responden memahami tentang penelitian ini dan seajara sukarela berpartisipasi dalam penelitian ini.

Tanda tangan peneliti.....Tanggal.....

8. Saya, yang bertandatangan di bawah ini telah membaca lembar persetujuan dan memberikan ijin bagi peneliti untuk menggunakannya sesuai penjelasan.

Tanda tangan responden.....Tanggal.....

9. Saya, yang bertandatangan di bawah ini, memberikan ijin kepada peneliti untuk mempublikasikan hasil penelitian ini.

Tanda tangan responden.....Tanggal.....



## Appendix 15 Nurse's interview guide

### Interview Guide

**Objective 1: To investigate what constitutes caregiving for older people with faecal incontinence in home-based care.**

1. How do you usually do to care for your older family member with faecal incontinence at home?
2. How effective are those measures to maintain the personal hygiene and the dignity of the older family member at home?
3. How did you get the information about care for older people with faecal incontinence?
4. How do you show your willingness to search the best management for faecal incontinence problem

**Objective 2: To investigate what are caregivers' perceptions of factors enabling and impeding their practice in managing faecal incontinence at home.**

5. What challenges you found when caring for older people with faecal incontinence at home?
6. What things motivate you to do your duties as primary caregiver for your older family member?
7. What are your experiences of using community-based services such as '*Posyandu Lansia*' (Integrated Service Post for Older People) to manage faecal incontinence in your older family member?
8. How useful do the health facilities in your environment in helping you to manage faecal incontinence at home?
9. What expectation do you have to the health facilities to ease you implementing your duty as a caregiver for the older people with faecal incontinence at home?

## **Appendix 16 Nurse's interview guide (Indonesian language)**

### **Pertanyaan Interview**

#### **Tujuan 1: Mengeksplorasi cara perawatan lansia yang tidak mampu mengontrol buang air besar di rumah.**

1. Bagaimana biasanya cara Anda merawat anggota keluarga Anda yang lansia yang sudah tidak mampu lagi mengontrol buang air besarnya?
2. Bagaimana efektifitas dari setiap cara yang anda lakukan dalam mempertahankan kebersihan dan martabat dari lansia anda dengan masalah ketidakmampuan mengontrol buang air besar?
3. Apa yang anda lakukan untuk memperoleh informasi tentang bagaimana cara anda merawat lansia yang sudah tidak mampu mengontrol buang air besar?
4. Bagaimana anda menunjukkan kesungguhan dalam mengusahakan perawatan terbaik bagi anggota keluarga yang sudah tidak mampu mengontrol buang air besar?

#### **Objective 2: Mengeksplorasi persepsi dari pemberi asuhan di dalam keluarga tentang factor yang mempermudah dan mempersulit dalam merawat anggota keluarga dengan ketidakmampuan mengontrol buang air besar.**

5. Tantangan apa yang Anda temukan saat merawat lansia yang sudah tidak mampu mengontrol buang air besar di rumah?
6. Apa hal-hal memotivasi Anda untuk melakukan tugas Anda sebagai pengasuh utama untuk lansia yang sudah tidak mampu mengontrol buang air besar lagi?
7. Bagaimana pengalaman Anda menggunakan layanan berbasis masyarakat seperti Posyandu Lansia dalam membantu merawat lansia anda di rumah?
8. Ceritakan pengalaman anda menggunakan pelayanan kesehatan yang ada dalam membantu melakukan tugas anda sebagai pengasuh utama?
9. Apa harapan Anda terhadap fasilitas kesehatan untuk memudahkan Anda menjalankan tugas Anda dalam melakukan tugas anda sebagai pengasuh lansia dengan fekal inkontinensia di rumah?

**Appendix 17 Examples of data analysis**

<b>Initial Words</b>	<b>Description</b>	<b>Open Codes</b>	<b>Group Codes</b>	<b>Themes/ Subthemes</b>
<p>“It’s incredibly smelly in the morning, but then after showering she will become clean and fragrant.” (P3, Line 7-8)</p> <p>Context: The caregiver is a daughter in law of the older person and replaces the diaper once in a day.</p>	Bathing the older family member is performed daily to overcome the bad smell.	Odour	Odour-management	Theme 1: Minimizing the detrimental impact of faecal incontinence on the care recipient
<p>“But, if we replaced the fabric and the diapers often, it will not be stinky, I suppose.” (P1, Line 413)</p> <p>Context: The caregiver has someone to help her to wash the fabric.</p>	Replacing fabric and diapers often will be useful to prevent odour.	Odour prevention	Odour management	
<p>“I also use soap even though it’s only in small amount because my mom cares about hygiene. If I only use wet tissue, I think it’s not as clean as using soap. I use the wet tissue twice.” (P4, Lines 22-23)</p> <p>Context: The older mother cares about hygiene.</p>	The caregiver uses wet tissue and soap to clean up the dirty areas.	Using soap & wet tissue	Hygiene	Theme 1: Minimising the detrimental impact of faecal incontinence on the care recipient  Sub-theme: Maintaining a good hygiene

<b>Initial Words</b>	<b>Description</b>	<b>Open Codes</b>	<b>Group Codes</b>	<b>Themes/ Subthemes</b>
<p>“I take care of my mother. Even though I’m in my business, I often come home to look after my mom, and then continue my social activities. Back and forth. I adjust my time. I will come home hourly.” (P4, Lines 163-164)</p> <p>Context: The caregiver is a health volunteer at Posyandu.</p>	<p>The caregiver needs to adjust her time to care and her routine.</p>	<p>Time adjustment</p>	<p>Time</p>	<p>Theme 1: Minimising the detrimental impact of faecal incontinence on the care recipient</p> <p>Sub themes: Time adjustment</p>
<p>“I will go from home in the morning, and return back in the afternoon. I won’t go away from home for a long time.” (P8, Lines 152)</p> <p>Context: The caregiver is the main caregiver who does not have any job, and the other family members have their own jobs.</p>	<p>Caregiver need to adjust time between her social activity and caregiving activity.</p>	<p>Time adjustment</p>	<p>Time</p>	
<p>“It’s just a little sharing. We all know that the older people are a little bit fussy. I think it’s normal. My mom complained when she felt that the diaper was uncomfortable. She would stop asking after we found the most comfortable one.” (P6, Lines 35-36)</p> <p>Context: There is no information of how to select absorbent products.</p>	<p>The caregiver was guided by the care recipient for choosing diaper.</p>	<p>Comfortable</p>	<p>Continence Aids-reasons</p>	<p>Theme 2: Continence aids</p> <p>Sub-theme: Reason for choosing or using continence aids</p>

<b>Initial Words</b>	<b>Description</b>	<b>Open Codes</b>	<b>Group Codes</b>	<b>Themes/ Subthemes</b>
<p>“I buy the diapers in Pramuka Market as it is cheaper there.” (P5, Line 120)</p> <p>Context: Pramuka Market is the famous market in Jakarta for buying health care aids as there people can find various health care aids with cheaper price.</p>	The caregiver tried to find the cheapest price.	Cost	Continen- Aids-reasons	<p>Theme 2: Continen- Aids</p> <p>Sub-theme: Reason for choosing or using continence aids</p>
<p>“The problem will definitely occur in the rainy season as my father doesn’t wear a diaper. We run out of fabrics. We cannot manage it.” (P9, Line 302-303)</p> <p>Context: The caregiver lives in two season country (rainy and sunny). The interview was taken in the rainy season.</p>	Caregiver struggles to provide fabrics in rainy season.	Fabric provision	Continen- Aids	
<p>“At the beginning I didn’t provide masks because I thought I could bear it as she is my mom. But then, if the faeces come out in large amounts I feel fed up and want to vomit. I do need to be wearing a mask.” (P4, Lines 74-75)</p> <p>Context: According to the caregiver she has a close relationship with her mother.</p>	The caregiver wears masks to avoid the odour.	Wearing mask for odour	Odour- management	<p>Theme 2: Incontinence aids</p> <p>Sub-theme: Adaptation to repulsion</p>

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