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ABSTRACT

Caring for an elderly person with dementia is a major life challenge and it entails emotional, physical, social and financial burden. It has also been described as one of the most difficult situations encountered by caregivers. The Purpose of the study was to describe how nurses care for the family members of patients with dementia in homecare in Norway.

A qualitative study design that was explorative, descriptive and contextual was used to purposively select nurses working in homecare in Norway. The sample consisted of eight nurses working in homecare with an experience of caring for patients with dementia. The sample size was determined by saturation. Data were collected using a semi-structured interview schedule and analyzed using content analysis.

The findings of our study showed that family members of patients with dementia experienced mental distress in form of anger, frustration and worry. The study also showed that nurses cared for the family members of patients with dementia by providing knowledge, psychosocial support and practical help. However, nurses experienced some challenges as they were caring for family members of patients with dementia. One of the challenges was seeking for help in the advanced stages of the disease which made it difficult for the family to appreciate the services offered to them. Another challenge was when the family members had inadequate knowledge about dementia which made it difficult for them to cooperate with the nurses.

In light of our findings, our recommendations to the Zambian health care system are that the homecare system needs to be reorganized and have more qualified personnel such as nurses to improve the quality of care to the patients. In addition, there is need to research on dementia and to have awareness programs at all levels of healthcare.

1.0 INTRODUCTION

Caring is a fundamental aspect of nursing practice. This is because it involves looking after and giving attention to someone in need. Nurses not only care for the patients but also for the family members because of the various effects a disease may pose on the family. Dementia is one such disease that may pose various challenges for family members.

Dementia is seriously disabling for those who have it and is often devastating for their caregivers and families. With an increasing number of people being affected by dementia, almost everyone knows someone who has dementia or whose life has been touched by it. The number of people living with dementia worldwide is currently estimated at 35.6 million and this number is likely to double by 2030 and more than triple by 2050 (World Health Organization, 2012).

Norway being a developed and high income country has advanced health technology and services; this has resulted in increased life expectancy of its citizens. Owing to this ever improving health services, the number of the elderly has risen considerably. This has brought a high prevalence of dementia and other diseases among the elderly (Norwegian Directorate of Health, 2009).

Longer life expectancy and changes in the age composition of the population is one of the biggest care challenges in Norway as it is expected that twice as many people in the next 35 years will have various dementia disorders. Today there are around 66,000 persons with dementia in Norway and approximately 250,000 close family members affected by dementia disorders. This means that around 30,000 places in nursing homes are occupied by persons with dementia, while only a tiny fraction of these places have been adapted to this user group (Norwegian Ministry of Health and Care Services, 2008).

As a result of the increasing number of persons with dementia, it is important to prepare the local community for this situation and provide better facilities for the patients and their families, who over many years often bear the heaviest burdens. In this context well developed home care services and day programmes play a crucial role (Norwegian Ministry of Health and Care Services, 2008). These homecare and day care services are important to the family members of patients with dementia as they may not have the time to provide the care that their relatives require. This could be attributed to the fact that in the Norwegian society 77% of

women and 84% of men are in the workforce and so may not be actively involved in the care of their relatives with dementia (Angell, 2008).

The authors of this paper are nurses from Zambia who were on an exchange program and had two weeks practical placement in home care nursing in Norway. The practical placement was done in a small district in a Norwegian municipality where most of the residents work in the industries. During the practical placement the authors observed how home nursing was organized and saw how patients were followed up at home. The authors also observed how the nurses had good relations with their patients in the municipality; this was as a result of them knowing each other as it was a small commune. The nurses in home care were assigned patients to visit and follow up and this was achievable because they had vehicles to use. All the services provided by the home care were free of charge including the medical/surgical supplies and equipment.

Being in Norway, the authors had an opportunity to participate in the care of patients with dementia and their families. As such, the focus of this study was on the care of family members of patients with dementia living in their homes.

Although dementia does not seem to be a big challenge for Zambia, the authors feel there is need to plan for the care of such patients and their families. As the nation strives to improve the healthcare system, the life expectancy of the people will increase and this may result in having more people with dementia.

1.1 STATEMENT OF THE PROBLEM

Caring for an elderly person with dementia is a major life challenge and it entails emotional, physical, social and financial burden. It also has been described as one of the most difficult situations encountered by caregivers (Shah and Wadoo, 2004). According to the WHO 2012 report on dementia, the provision of care to a person with dementia can result in significant strain for those who provide most of that care which can be physical, emotional and economic.

Dementia is a clinical syndrome with multiple aetiologies that particularly affects older people. Given the seriousness of the impact of dementia, the ageing of the world's population, and that the prevalence of dementia increases with age, a lot of attention is understandably

now focused on the treatments, care services and support arrangements needed by people with dementia and their families – both today and over the coming decades (Knapp et al, 2007).

Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. It is one of the major causes of disability and dependency among older people worldwide. Dementia has an immense impact on the lives of the family, and particularly the person who takes the primary role in providing care. Most care is provided by family and other informal support systems in the community and most caregivers are women (WHO, 2012).

Being a family caregiver for a person with dementia can be very burdensome (Norwegian Ministry of Health and Care Services, 2008). This is because family members are faced with numerous difficult decisions such as when the patient should stop driving and when to assume responsibility for the patients' financial affairs. Aggression and hostility exhibited by the patient are often misunderstood by families or care givers, who feel unappreciated, frustrated, and angry. Feeling of guilt, nervousness, and worry contribute to care giver fatigue, depression, and family dysfunction. In some cases, care givers themselves can become so fatigued as a result of the stress of care giving that self-neglect, or neglect or abuse of the patient can occur (Smeltzer et al, 2008).

Caring for a person with dementia increases the risk of harm to the health of the caregiver. This is because caring for a patient with dementia requires a lot of time and energy and the demand increases as time goes on. Therefore, families need information about dementia disorders, relevant treatment and available support mechanisms in order for them to cope with the demands of care (Norwegian Ministry of Health and Care Services, 2008).

As nurses, it is imperative that we support family caregivers so as to create good quality services for the individual as well as to provide relief for families (Norwegian Ministry of Health and Care Services, 2008).

1.2 PURPOSE OF THE STUDY

The Purpose of the study is to describe how nurses care for the family members of patients with dementia in homecare in Norway.

1.3 TENTATIVE RESEARCH QUESTIONS:

- To find out how nurses care for the family members of patients with dementia in homecare in Norway.
- To explore the experiences of nurses caring for the family members of patients with dementia in homecare in Norway.

2.0 REVIEW OF THE LITERATURE

In order to understand how Nurses care for family members of patients with dementia it is important to know about the historical development of the welfare state and how it has influenced the organization of home care services in Norway. The historical development of the welfare state in Norway can be traced back to the 19th century. The decades following World War II brought about the founding of one of the world's most comprehensive welfare systems. The development of the Norwegian welfare state was influenced by crisis and war, social democracy, economic growth and full employment (Aase and Silve-linn, 2008). It is based on the idea that the state is responsible for the welfare of its people.

The Norwegian state has been very active in introducing measures aiming at equalizing access to material goods and benefits (Aase, 2008). The aim of the welfare state has been to fight what was considered the five main evils in society: poverty, illness, unemployment, ignorance and bad housing conditions. In other words: each member of the Norwegian society should have equal access to work, education, health care and a house to live in (Aase, 2008). Due to the evils that existed, this prompted the Norwegian society to formulate different policies to deal with the problems. This saw the coming in of different policies, for example social equality which entails that people should have equal opportunities in life regardless of where they were born or who their parents were.

Further, this meant men and women having equal opportunities to work unlike in the past where most women stayed at home to care for the children and the elderly. For instance in 1965, 9 out of 10 mothers with small children were house wives. Today the situation has been nearly reversed due to the emergence of a strong system of public welfare and an explicit policy aimed at helping women and men to reconcile the demands of family and working life. As such, the state has developed kindergartens, nursing homes and homecare as a result of the shift in the care of the children and the elderly which was mostly done by women (Angell, 2008).

Norway being a welfare state has a health care system built on the principle of equal access to services. It states that all inhabitants of the country shall have the same access to services, independent of the persons' social status, location and income. To fulfill this, the organizational structure has three levels namely National, Provincial and Local level (Angell, 2008). The local level is entrusted with the provision of a wide variety of primary health

services. Among the primary health services is the health and care services for the elderly and disabled which includes health and medical services, nursing homes, home based care and services, assistance at home and community nursing, relief services for family members and day care and activity centres (Norwegian Directorate of Health, 2009).

Care for the patients with dementia can either be provided through the home care services, nursing homes and apartments. Home nursing services are provided on a 24-hour basis to assist with various care needs and patients' families are free to call should they be in need. There is a 24-hour national dementia helpline where people can call if they need help or information. There is also a school of relatives where family members of patients with dementia can learn about dementia and how to care for the patients at home. The school of relatives also serves as a place where family members of patients with dementia can share experiences on caring.

Looking at Norway which is a high modern society, it embraces both collectivistic and individualistic cultural characteristics (Neuliep, 2006). Although it embraces both types of cultural characteristics, most families have adopted the individualistic culture where people live as individuals, look after themselves and their direct family only. According to Halvorsen (1999), the Norwegian welfare state makes individuals independent from family relations and individual responsibility. As a result of this, an elderly person with dementia may live with their family or alone.

On the other hand the Zambian society is more collectivistic than individualistic. Collectivistic societies are characterized by extended primary groups such as the family, neighbourhood, or occupational groups in which members have diffuse mutual obligations and expectations based on their status or rank. In collectivistic cultures people are not seen as isolated individuals. People see themselves as interdependent with others where responsibility is shared and accountability is collective. A person is not seen as an individual but as a member of a group (Neuliep, 2006). Looking at the Zambian society which is collectivistic families are closely knitted together with strong links to their relatives. As such the elderly live and are looked after by the extended family.

Dementia is a broad term for a syndrome characterized by a general decline in higher brain functioning, such as reasoning, with a pattern of eventual decline in ability to perform even basic activities of daily living, such as toileting and eating (Smeltzer et al, 2008). The most important symptom or characteristic of dementia is impaired memory. Dementia also results

in impairments in thinking, communication and orientation. Persons affected by dementia have difficulty performing habitual tasks or coping with everyday problems. Some develop personality changes featuring a lack of insight and poor judgment, lack of inhibitions, aggressiveness and a lack of empathy. Other symptoms are anxiety, depression, suspiciousness, delusions and compulsive behaviours (Norwegian Ministry of Health and Care Services, 2008). Dementia is a progressive disease and those who suffer with dementia gradually lose the ability to live independently without the assistance of others (Shah and Wadoo, 2004).

Caring for the family members of patients with dementia is very important considering the stresses that can be brought about by changes in patients' behaviour. Therefore it is intuitive to consider the Stress Process Model as a theoretical base for exploring the experience of caring for a family member of a patient with dementia.

The Stress Process Model (SPM) was developed by Pearlin in 1989. The SPM has six components which are:-

(a)*Background and context* are contextual antecedent characteristics that influence the stress and any subsequent outcomes that stem from that stress, for example socio-demographic characteristics such as culture, family network and personal history.

(b)*Primary stressors*; "are conditions, experiences, and activities that are problematic for people; that is that threaten them, thwart their efforts, fatigue them, and defeat their dreams" (Pearlin et al., 1990). The primary stressors include the care recipient's behaviour, care recipients needs and carers' subjective stress.

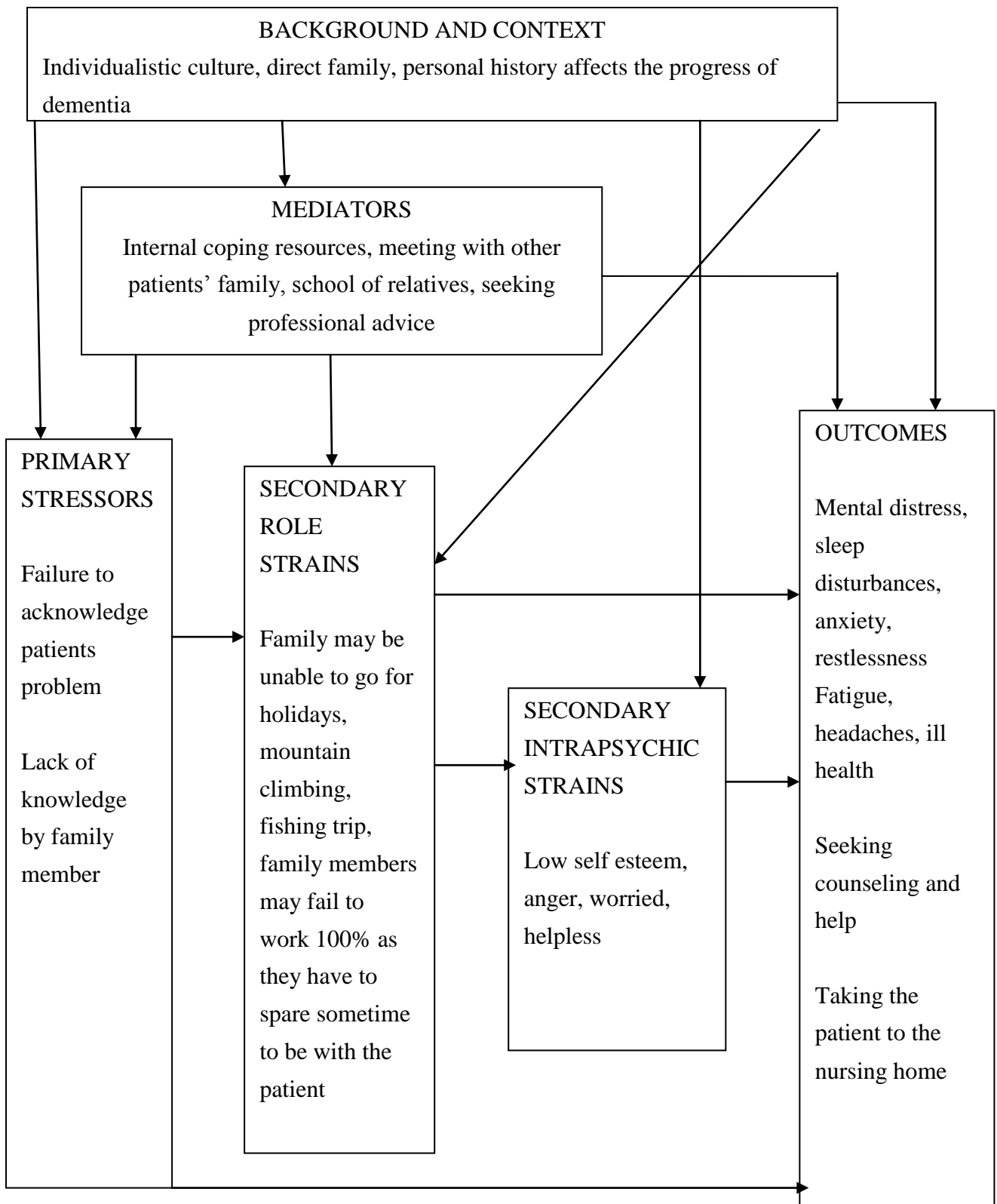
(c)*Secondary role strains* and (d) *secondary intrapsychic strains*

Secondary role strains consider those non-caregiving roles that may be compromised by the activity of caregiving e.g. family, social life and economic problems. A caregiver's self-concept and personality states that are possibly influenced by caregiving are considered *secondary intrapsychic strains*. A basic premise of this Stress Process Model is that "one set of stressors can lead to another" (Pearlin et al., 1990); therefore it is important to understand the notion that primary stressors, those directly related to caregiving, may in turn have an impact on role strains and intrapsychic strains, which may or may not be directly related to caregiving.

(e) *Outcomes* result from the stressors and are often related to an individual's wellbeing. Other items that serve as outcomes may be physical and/or mental health, and the ability to sustain social roles.

(f) *Mediators* “have been shown to govern (or mediate) the effects of stressors on stress outcomes” (Pearlin et al., 1990). Mediators include internal coping resources and social support.

THEORETICAL FRAMEWORK OF THE STRESS PROCESS MODEL



(Pearlin et al., 1990)

According to the Stress Process Model, caring for family members of patients with dementia possess a lot of stress on the family member. Several studies have been done on various aspects of caregiving and have shown both positive and negative effects.

In a study done by Reinhard et al (2008) on supporting family caregivers in providing care in the USA, it was noted that both highly negative and highly positive consequences of providing care may exist simultaneously. It is plausible that positive consequences, such as rewards and satisfaction, may buffer the negative effects of caregiving. Caregivers who attempt to balance caregiving with their other activities, such as work, family, and leisure, may find it difficult to focus on the positive aspects of caregiving and often experience more negative reactions, such as an increased sense of burden.

Regardless of amount of care provided, caregivers may become increasingly more distressed if they are unable to participate in valued activities and interests. Caregiving responsibilities can have a negative effect on work roles as caregivers adapt employment obligations to manage and meet care demands. Caregivers who are employed report missed days, interruptions at work, leaves of absence, and reduced productivity because of their caregiving obligations. They have difficulty maintaining work roles while assisting family members. On the other hand, employment provides some caregivers respite from ongoing care activities and serves as a buffer to distress (Reinhard et al, 2008).

Providing adequate knowledge to the family is important. According to Reinhard et al (2008), in their study of supporting family caregivers in providing care in the USA, it was found that if family caregivers had inadequate knowledge and skill, family caregivers would be unfamiliar with the type of care they must provide or the amount of care needed. Family caregivers may not know when they need community resources, and may not know how to access and best utilize available resources. Therefore interventions to increase caregivers' knowledge about community services and how to access them can increase their sense of competence and reduce depression.

In the same study on supporting family caregivers in providing care in the USA, Reinhard et al (2008) further noted the need for family members to interact with the health care system to obtain information, services, and equipment, as well as to negotiate with family and friends to enlist and mobilize support.

In another study conducted by Charlesworth et al (2011) in England on peer support for family carers of people with dementia, it was noted that family carers may experience social

isolation through lack of personal time and opportunities to socialize, and stigma resulting in family and friends distancing themselves. Without support, family carers can feel emotionally and physically burdened and may experience interrelational conflicts, which may reduce perceived level of emotional support and increase feelings of loneliness. It has been suggested that peer support can directly improve wellbeing by decreasing feelings of isolation and/or encouraging more appropriate coping strategies, and enabling a change in behaviour, emotion or cognitions.

Further in the same study done by Reinhard et al (2008) in USA on supporting family caregivers in providing care, it was found that if the care recipient wanders or displays unsafe behavior, the caregiver has to be alert and on call for supervision 24 hours per day. The constant concern for managing disruptive behaviors such as turning on stoves, walking into the street, taking too many pills, yelling, screaming, or cursing also affects the caregivers negatively. Teaching caregivers how to manage specific patient problems can improve the caregiver's well-being. For example, not being able to sleep at night is a serious problem for caregivers of people with Alzheimer's disease, as the caregivers become fatigued and exhausted, which can have an adverse effect on both the physical and emotional health of the caregiver.

Albinsson and Strang (2003), in their study on the differences in supporting families of dementia patients and cancer patients, found that it was significantly more important to form support groups for families, to offer respite care, to educate families and to try to relieve the family's feeling of guilt. In a related study done by Reinhard et al (2008) on supporting family caregivers in providing care in the USA, it was found that the use of respite/day care significantly lowered stress, anger and depression among caregivers.

3.0 RESEARCH DESIGN AND METHODOLOGY

Research methodology is a technique used to structure a study and to gather and analyze information in a systematic fashion (Polit and Beck, 2010). It outlines the research design, study population, sample selection, data collection tool and techniques to be used in the study, pilot study and ethical considerations.

3.1 RESEARCH DESIGN

Basavanthappa (2007) defines research design as “the plan, structure and strategy of investigations of answering the research questions”. It is the overall plan or blue print the researchers select to carry out their study.

In this study, the researchers used a qualitative method that was explorative, descriptive and contextual in order to gain a rich understanding of the phenomenon as it existed in the natural setting. According to Creswell (1994) “A qualitative study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting”.

3.2 DATA COLLECTION METHODS

Data collection tool or method is a measuring device used in gathering information needed to address a research problem. It may take the form of a questionnaire or interview schedule, checklist, projected device or some other type of tool for eliciting information (Polit and Beck, 2006). In this study, a semi-structured interview schedule was used to collect data. A semi-structured interview schedule is one that contains structured and unstructured questions with standardized and open type questions (Walliman, 2011).

Advantages of a semi-structured interview

- In-depth interviews allow researchers to collect a great deal of relevant information in a short period of time.
- Informants are able to provide detail about their personal experiences, views, and behaviour.

- The audiences are specifically targeted.
- Can be used for sensitive topics (Longfield, 2004).

Disadvantages of using a semi-structured interview

- Time consuming and resource intensive (Longfield, 2004)
- Interviewing skills are required.
- Preparation must be carefully planned so as not to make the questions prescriptive or leading.
- Need to have the skills to analyze the data (Cramer and Howitt, 2011)

3.3 POPULATION

Population in research is a collective term used to describe the total quantity of things (or cases) of the type which are the subject of your study. So a population can consist of certain types of objects, organizations, people or even events (Willaman, 2011). In this study our population comprised of nurses working in homecare in Norway.

3.4 SAMPLE

A sample is a subset of a population selected to participate in a study (Polit and Beck, 2010). In this study, the researchers used purposive sampling. Purposive sampling is a method which groups participants according to preselected criteria relevant to a particular research question (Mack et al, 2011). It aims at selecting particular study units that yield the most relevant and plentiful data (Yin, 2011). The sample consisted of nurses working in homecare with an experience of caring for patients with dementia. Nurses from two different communities in the same municipality were interviewed to find out how nurses care for family members of patients with dementia in homecare in Norway. The sample size was determined by saturation. Saturation is the collection of qualitative data to a point where a sense of closure is attained because new data yield redundant information (Polit and Beck, 2010).

3.5 DATA COLLECTION TECHNIQUE

Data collection technique is the actual method of how the data will be collected (Polit and Beck, 2006). The researchers conducted the interviews in a private room at the work place. The interviews were conducted after the informants had signed the consent forms. During the interviews, there were three researchers each with different roles. One was conducting the interview, the other was clarifying the questions and the other one was taking notes.

3.6 TRUSTWORTHINESS

Lincoln and Guba (1985) in Polit and Beck, 2010 suggested four criteria for developing the trustworthiness of a qualitative inquiry: credibility, dependability, confirmability, and transferability.

Dependability refers to the stability (reliability) of data over time and over conditions. The dependability question is “would the study findings be repeated if the inquiry were replicated with the same (or similar) participants in the same (or similar) context?” (Polit and Beck, 2010). In our study dependability was ensured by using the same interview schedule to collect data from the different respondents.

Confirmability refers to the objectivity that is, the potential for congruence between two or more independent people about the data’s accuracy, relevance, or meaning. This criterion ensures that the data represent the information that the participants provided, and that the interpretations of those data are not figments of the inquirers imagination (Polit and Beck, 2010). In this study, the researchers ensured confirmability by ensuring that data were written exactly as it was given by the respondents.

Credibility refers to confidence in the truth of the data and interpretations of them. The credibility criterion involves establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research. Credibility was ensured by recording the respondent’s responses exactly as they were given.

Transferability analogous to generalizability, refers to the extent to which qualitative findings can be transferred to (or have applicability) other settings or groups (Polit and Beck, 2010). In ensuring that the data was transferable the researchers provided sufficient descriptive data in the research report.

3.7 PILOT STUDY

A pilot study is a small-scale version, or trial run, done in preparation for a major study (Polit and Beck, 2010). The primary objective of a pilot study is to test as many elements of the research proposal as possible, in order to correct any part that does not work well. The researchers carried out a pilot study on two nurses working in homecare services in Norway. The pilot study helped the researchers to identify and make changes to the interview schedule. For example question six which read as “How do you support family members of the patients with dementia in the following areas: accessibility and utilization of community resources” was changed to be a separate question and read as “Are there any community resources that can be accessed and utilized by family members of patients with dementia?” The pilot study also helped the researchers to share the roles during the interview such as interviewing, clarifying and taking notes. It also helped the researchers to plan how long an interview would take. In the pilot study, the interview lasted fifteen minutes for each interviewee. The data obtained from the pilot study was included in the analysis because it yielded information that was valuable and relevant to the study.

3.8 ETHICAL CONSIDERATIONS

Ethics are systems of moral values that are concerned with the degree to which research procedures adhere to the professional, legal and social obligations to the study participants (Polit and Beck, 2006). Our study respondents were selected because they were not vulnerable. The researchers informed the respondents that participation was voluntary meaning that respondents were free to withdraw from the study at any time. Confidentiality was maintained by ensuring that the names of the respondents and the name of the work place did not appear on the interview schedule. The researchers also ensured that information provided was not to be publicly reported in a manner that identified the respondents. Informed consent was obtained verbally and in written. The consent forms were kept separate from the interview schedules. The interview was conducted at the work place in a private room to maintain privacy and prevent disturbances. Permission to carry out the study was obtained from the Head of the homecare services in the municipality.

4.0 DATA ANALYSIS

Data analysis is a mechanism for reducing and organizing data to produce findings that require interpretation by the researcher (Burns and Grove, 2009). The main purpose of data analysis is to derive meaning and interpretation from the research findings. In this study, qualitative data were collected using an interview schedule. Data was analyzed using content analysis, which is the process of organizing and integrating narrative, qualitative information according to emerging themes and concepts (Polit and Beck, 2010). In this study, data was analyzed manually by reading through to identify meaningful segments and units. The segments were reviewed and finally concepts and themes were categorized.

In our study, eight respondents were interviewed and each interview took ten (10) minutes. The nurses were willing to participate in the study. From our observations the nurses found it interesting and were pleased to work in homecare with family members of patients with dementia.

The respondents were nurses working in homecare from 4months to 13years. The number of patients with dementia who were being cared for by the home nursing was twenty (20) from two different communities in the same municipality. The age range of the patients with dementia was between 80-90 years.

The following are the themes that were identified

Mental Distress

From the nurses' experience on how it is to care for family members of patients with dementia, some form of mental distress was observed among family members. This was expressed through frustration, anger and worrying.

Frustration: the nurses said the relatives of patients with dementia experience frustration especially when they have little education about how to care for the patient with dementia. Frustration also comes if the patient cannot recognize the family members. One nurse said *“the family feels they have lost the patient while he/she is still alive.....some family gave out the patients things because they felt they had lost the patient”*.

The other nurse said that; *“it is not easy to have a patient with dementia in the home...the family feels tired and frustrated”*.

Another mentioned that *“it is difficult for family members to understand if the development of dementia is acute as the patients’ condition keeps on changing and it is frustrating”*.

Anger: family members of patients with dementia experience anger especially when they cannot understand the patients’ language, behaviour and memory loss.

One nurse said *“in the beginning the relatives become confused about the patients’ behaviourone man went out without a trousers and the wife was very annoyed”*.

Family members also experience anger when the patient with dementia loses language, is angry and frustrated as they cannot understand each other.

As one nurse expressed *“It can be difficult to care for a patient with dementia....the dementia patient can be angry, frustrated.....others cannot speak and they cannot understand each other with the family member”*.

Worrying: most of the family members of patients with dementia are worried of the patients’ safety. They fear that the patient may leave electrical appliances on such as the heater, stove, pressing iron and coffee maker which may be dangerous for the patient. They also fear that the patient may leave the tap on or even wonder away in the night.

How nurses care for the family members of patient’s with dementia

Knowledge needs of family members

The nurses provide information and educate the family members of patients with dementia through the school of relatives. Family members are given brochures with information about dementia and are also taught how dementia can develop to help them understand the patients’ behaviour.

The nurses mentioned that *“We also teach them how dementia can developexplain to them that dementia is a normal illness”*.

The school of relatives also serves as a place where family members of patients with dementia can learn about how to communicate with the patient and how to care for the patient at home.

One of the nurses said that *“We educate family members on how to communicate with patients and how to care for them”*.

The family members are also taught about the use of a contact book which is used to share information among the family, nurses, home help and home cleaning services.

“We give them information about dementia and have a contact book where we the nurses, home help, cleaning services and the family can share information.....if there is a problem we increase the number of visits to the patient without them having to ask for it”.

Psychosocial support

Family members of patients with dementia receive psychosocial support through the school of relatives where the family can be able to ask questions and air out their concerns. The family members are also able to meet with other patients' families and share experiences at the same time learn from each other.

The nurses said *“We tell them they are not alone with the problem”.....we talk to the family members about the disease so that they understand that it is not the patient but the disease”*

Family members are also free to meet individually with the nurses and doctors if they need more information. They are free to call the dementia helpline at any time should they have a problem.

There is a Time center under the dementia program where patients are taken every Tuesdays and Thursdays for coffee trips and other activities. This gives the family some time off to care for the patient and also enable them do other activities. During these trips, the nurses are able to observe for any changes in the patients' condition.

The other service offered to relieve family members from care burden is the day place services where patients are taken to have breakfast and supper. For patients who are severely demented, they are taken to the nursing home for a week or two in order for the family to have relief.

Practical help

Practical help to the family members of patients with dementia is provided through home visits where patients are helped with medications, bathing and dressing, shopping, food, home

cleaning services and making appointments with the hair dresser. The nurses also assessed the need for safety devices such as circuit breakers to be installed on cookers and coffee makers to reduce the risk of fire accidents in the patients' home.

Accessibility and utilization of community resources

The special dementia program has a bank account with funding from the commune which is used for purchasing equipment and food for patients with dementia. The commune has a house specifically adapted for patients with dementia which has colour coded signs to help them identify things easily. The commune also pays for the installation of fire alarms, circuit breakers and timers in the patient's home.

"Patients have fire alarms, timers and circuit breakers paid by the commune..... the family wants it....it makes them feel secure" as expressed by one nurse.

Experiences of nurses caring for family members of patients with dementia

Caring for family members of patients with dementia can be rewarding to both the nurses and the patients' family. When family members have adequate knowledge about dementia, there is cooperation between the nurses and the family as they are able to understand the need for care. When family members understand what dementia is and how to care for the patient, they are able to participate in the assessment of the patient. However, nurses can face some challenges when caring for family members of patients with dementia. For example one nurse expressed that *"If the family denies that their patient is sick, there is usually no cooperation between the home nurses and the family"*.

When family members of patients with dementia have little knowledge about dementia, it is difficult for them to understand the changes caused by dementia and the need for care. As mentioned by one nurse *"If the family does not understand what dementia is, it is difficult for them to accept the condition and the need for care"*.

Furthermore another nurse said that it was difficult to work with family members who had different opinions as to whether the patient should be at home or at the nursing home.

When family members seek for help in the advanced stages of the disease, it is difficult for them to appreciate the nursing services being offered to them as stated by the nurses *"It is*

difficult to care for families if they call for home care when the disease has advanced, they do not understand and appreciate what the nurses are doing for them.....the family wants much more than we can offer.... they want us to fix everything”.

The nurses also mentioned that *“It is a challenge to care for the family members if the patient needs close monitoring and the nurses are few especially in the evening shift.....sometimes it is not easy to leave them”.*

5.0 DISCUSSION

Mental distress

Caring for family members of patients with dementia is very important. Findings of our study revealed that as nurses care for family members of patients with dementia, the family members exhibited mental distress in form of anger, worry and frustration. According to the stress process model mental distress can result from stress which the family caregiver undergoes when caring for the dementia patient. The family members of patients with dementia experienced frustration especially when they had little knowledge about dementia and how to care for the patient. Reinhard et al 2008 in their study on supporting family caregivers in providing care found that if family caregivers had inadequate knowledge and skill, they would be unfamiliar with the type of care they must provide or the amount of care needed. This could probably lead to frustration in the family member as they had little knowledge on how to care for the patient. Our study also revealed that memory loss and failure of patients to recognize family members was also a source of frustration to the family. Furthermore the study showed that family members of patients with dementia experienced anger especially when they could not understand the patients' language, behaviour and memory loss.

Our study also showed that most of the family members of patients with dementia were worried of the patients' safety. They feared that the patient may leave electrical appliances on which may be dangerous for the patient. They also feared that the patient may leave the tap on or even wander away in the night. Similarly, Reinhard et al 2008, in their study on supporting family caregivers in providing care, found that if the care recipient wanders or displays unsafe behavior, the caregiver had to be alert and on call for supervision 24 hours per day. The constant concern for managing disruptive behaviors such as turning on stoves, walking into the street, taking too many pills, yelling, screaming, or cursing also affected the caregivers negatively. The family members of patients with dementia were usually worried about the patients' safety due to the progressive nature of the disease and unpredictable behaviour of the patient which put them at risk especially that most of them lived alone. Most of the patients lived alone because Norway is a high modern society which embraces an individualistic culture where people live as individuals; look after themselves and their direct

family only. In a high modern society according to Giddens (1991) an individual is freed from externalities associated with pre-established ties to other individuals and groups. This means that a person is responsible to decide for themselves where to live and how to spend one's old age. In addition, the Norwegian welfare state also makes individuals independent from family relations and individual responsibility (Halvorsen 1999).

How nurses care for the family members of patient's with dementia

Knowledge needs of family members

On knowledge needs of family members of patients with dementia, our study findings showed that nurses provided information and educated the family members of patients with dementia through the school of relatives. Family members were given brochures with information about dementia and were also taught how dementia develops to help them understand the patients' behaviour. Furthermore, family members of patients with dementia were taught on how to communicate with the patient and how to care for the patient at home. In a study conducted by Albinsson and Strang (2003), on the differences in supporting families of dementia patients and cancer patients, it was found to be significantly more important to educate families of Dementia patients. Similar findings were noted by Reinhard et al (2008) in their study of supporting family care givers in providing care that teaching caregivers how to manage specific patient problems could improve the caregiver's well-being. This finding could probably be due to the fact that if family members had inadequate knowledge about dementia, they would not be confident with the type and amount of care to provide to the patient.

Psychosocial support

With regard to psychosocial support, results of our study showed that family members of patients with dementia received psychosocial support through the school of relatives where the family could ask questions and air out their concerns. Through the school of relatives, the family members were able to meet with other patients' families, shared experiences and at the same time learnt from each other. According to the stress process model the meeting of family members of patients with dementia with others can be likened to mediators which govern the

effects of stress and outcomes. These mediators can be internal coping resources and social support (Pearlin et al, 1990).

Apart from the school of relatives, the nurses gave psychosocial support by reassuring the family members that they were not alone with the problem and they also explained about dementia to help them understand the patients' behaviour. Psychosocial support was given through meetings between family members and the doctors and through the 24 hour National dementia helpline.

There was also a time center and day place services were patients were taken care of by the nurses. The time center and day place services gave the family some relief from caregiving and enabled them to do other activities. Albinsson and Strang (2003), in their study on the differences in supporting families of dementia patients and cancer patients, found that it was significantly more important to form support groups for families and to offer respite care. In a related study done by Reinhard et al (2008) on supporting family caregivers in providing care in the USA, it was found that the use of respite/day care significantly lowered stress, anger and depression among caregivers. This finding could be attributed to the fact that respite care was important for family members of patients with dementia as it enabled them to rest from caregiving and do other activities. Therefore if family members were not relieved from the burden of caregiving, they could experience mental distress in form of anger, frustration and worry. Charlesworth et al (2011) in their study on peer support for family carers of people with dementia found that without support, family carers can feel emotionally and physically burdened and may experience interrelational conflicts, which may reduce perceived level of emotional support and increase feelings of loneliness. In the same study it was suggested that peer support can directly improve wellbeing by decreasing feelings of isolation and/or encouraging more appropriate coping strategies.

Practical help

Concerning practical help to the family members of patients with dementia, findings of our study revealed that the nurses helped with giving medications, bathing and dressing. They also helped with shopping, food, home cleaning services and making appointments with the hair dresser. In a study done by Andrén and Elmståhl, 2008 on effective psychosocial intervention for family caregivers in Sweden, it was found that similar services were offered by the Swedish municipality, which included personal care (personal hygiene, getting

dressed), practical assistance (housework, laundry, shopping), provision of meals-on-wheels, and also other complementary services such as relief service and companion service. This finding could be attributed to the fact that most patients lived alone or with family members who worked and therefore it was not possible for the family members to give practical help to the patient. It can also be attributed to the fact that Norway is a welfare state in which the Municipality is responsible for providing such services to the people. Providing practical help to the family members of patients with dementia was very important as it enabled the family to have some time to relax and do other activities.

Our study also revealed that the nurses assessed the need for safety devices such as circuit breakers to be installed on cookers and coffee makers to reduce the risk of fire accidents in the patients' home.

Accessibility and utilization of community resources

Regarding accessibility and utilization of community resources, our study revealed that the commune had an account where money could be withdrawn and used for purchasing equipment and food for patients with dementia. The commune had a house specifically adapted for patients with dementia which had colour coded signs to help them identify things easily. The commune also paid for the installation of fire alarms, circuit breakers and timers in the patient's home. This finding could be due to the fact that Norway being a welfare state provided care for the elderly including the dementia patients through the commune. Therefore, it was important for the family members of patients with dementia to know about the community resources and how to access them.

Experiences of nurses caring for family members of patients with dementia

Findings of our study revealed that when family members had adequate knowledge about dementia, there was cooperation between the nurses and the family as they were able to understand the need for care. When family members understood what dementia was and how to care for the patient, they were able to participate in the assessment of the patient. This result could be attributed to the fact that family members were taught at the school of relatives about dementia and how to care for the patient at home. Caring for the family members of

patients with dementia could be rewarding to both the nurses and family members if the family had knowledge as it was easy for them to understand each other.

However, nurses can face some challenges when caring for family members of patients with dementia. Our study findings revealed that if the family denied that their patient was sick, there was no cooperation between the home nurses and the family. It also showed that when family members of patients with dementia had little knowledge about dementia, it was difficult for them to understand the changes in patient's behaviour and the need for care. Furthermore it was difficult to work with family members who had different opinions as to whether the patient should be at home or at the nursing home. It was also revealed that when family members sought for help in the advanced stages of the disease, it was difficult for them to appreciate the nursing services offered.

5.1 METHODOLOGICAL STRENGTHS AND WEAKNESSES

The researchers used a qualitative method to enable them collect in-depth information about the phenomena under study. The researchers shared roles during the data collection which enabled them to record information accurately from the respondents. Most of the respondents had knowledge about dementia and the programs in the commune and were willing to participate in the study. Trustworthiness in our study was ensured by recording the responses exactly as they were given by the respondents. The researchers also provided sufficient descriptive data in the report. Trustworthiness was ensured throughout our study as our findings are similar to those found by other researchers.

However, it was difficult for some respondents to give a lot of explanations in English as it was not their primary language. It was also difficult for the researchers to find relevant literature on how nurses care for the family members of patients with dementia as most of the literature was on the care of patients with dementia.

5.2 CONCLUSION

Caring for family members of patients with dementia is a very important aspect of dementia care considering the many challenges that family members face when caring for the patients. The aim of the study was to explore how nurses care for the family members of patients with

dementia in homecare in Norway. The findings of the study showed that nurses care for the family members through the school of relatives where they learn and share experiences about how to take care of the patients. The nurses also offer psychosocial support, practical help and respite care to enable the family members of patients with dementia have some time off from caregiving. Our study also showed that the nurses experienced challenges when caring for family members of patients with dementia especially when the family members had inadequate knowledge about dementia and if they had different opinions about how to care for the patient. It was also a challenge to care for the family members of patients with dementia if they sought for help in the advanced stages of the disease as they could not cooperate and appreciate what the nurses were doing for them.

Looking at the two countries with different cultural backgrounds, family members of patients with dementia are affected in one way or the other because of the progressive nature of the disease and the strain it causes on the caregiver. Therefore, it is important to care for the family members of patients with dementia. Although the problem of dementia is not a big challenge in Zambia, there is need to plan for the resources and management of patients and families because of the complex nature of the disease. The need to plan is necessary owing to the increasing life expectancy of the people which may increase the number of people with dementia.

5.3 RECOMMENDATIONS

The following are our recommendations:

Norwegian homecare services

- There is need to have the school of relatives in all communes since the problem of dementia is common to all.
- There is need for more awareness programs so that people can seek for help in the early stages of the disease.

Zambian health care system

- The homecare system needs to be reorganized and have more qualified personnel such as nurses to improve the quality of care given to the patients.
- Committees should be formed in various districts where nurses can share knowledge on how to manage patients with dementia.

- There is need for dementia awareness programs at all levels of healthcare. Information about dementia should be disseminated in the local languages.
- Family members of patients with dementia should be educated on how to care for their patients at home since most of them live with the family and it is their responsibility to care for them.
- There is need for research on dementia to ascertain the extent of the problem

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Appendix 1

We are Nurses from Zambia doing Global Knowledge at Høgskulen I Sogn og Fjordane, Faculty of Teacher Education and Sport. As part of our examination in Global Knowledge we are required to undertake a research study and our topic is: “*Caring for Family Members of Patients with Dementia in Homecare in Norway: A Nurses’ Perspective*”.

CONSENT FORM

I understand that my participation in this study is entirely voluntary, and I may withdraw from the study at any time I wish. I understand that during the study, I will be required to give information about caring for family members of patients with dementia.

I understand that my participation in the study will not benefit me in terms of financial and material gains. However, the information I will provide will help the students know more about how family members of patients with dementia are cared for.

I understand that all study data will be kept confidential. However, this information may be used in nursing presentations.

The study has been explained to me. I have read and understand this consent form, all of my questions have been answered and I agree to participate.

Signature of participant

Date

Signature of investigator

Date

Appendix 2

**SOGN OG FJORDANE UNIVERSITY COLLEGE
FACULTY OF TEACHER EDUCATION AND SPORT
GLOBAL KNOWLEDGE 301**

INTERVIEW SCHEDULE

**TOPIC: CARING FOR FAMILY MEMBERS OF PATIENTS WITH DEMENTIA IN
HOMECARE IN NORWAY: A NURSES' PERSPECTIVE**

Serial Number: _____

Date: _____

Demographic data:

1. For how long have you been working as a nurse? _____
2. For how long have you been working with the home care service?

3. How many patients with dementia are you caring for at the moment?

4. In what age ranges are the patients?

Care for the family:

5. How is it for a family member to care for a relative with dementia from your experience?

- Do you have any examples

6. How do you support family members of the patients with dementia in the following areas:-

- knowledge needs of the family members

- psychosocial support

-
-
- practical help to the family

7. Are there any community resources that can be accessed and utilized by family members of patients with dementia?

8. What other sources of support are available for the family members of patients with dementia in your municipality?

Challenges:

9. Could you explain the challenges that you face when caring for family members of patients with dementia?

Appendix 3

Høgskulen I Sogn og Fjordane,
Faculty of Teacher Education and Sport
6856, Sogndal.

The Head
Home care service
Årdal Kommune
Sogn og Fjordane.

RE: PERMISSION TO CONDUCT A RESEARCH PROJECT

We are Nurses doing Global Knowledge at Høgskulen i Sogn og Fjordane Faculty of Teacher Education and Sport. As part of our examination in Global Knowledge, we are required to undertake a research project. Our topic is “**Caring for The Family Members of Patients with Dementia in Homecare in Norway**”.

We write to request your office for permission to conduct research at your institution starting from the 6-9th March, 2012. Attached are copies of our interview schedule and consent form.

If you need further details and clarifications please contact our supervisor, Randi Jepsen at the Faculty of Health Studies. You can contact her on 57722577, email Randi.Jepsen@hisf.no.

Your favourable consideration of our request will be highly appreciated.

Yours faithfully,

Nelia Langa, Bupe Simwanza and Regina Muchelenje

Appendix 4

Høgskulen i Sogn og Fjordane
Faculty of Teacher Education and Sport
6856, Sogndal

The Head Nurse
Home Care Service
Årdal Kommune
Årdal

RE: PERMISSION TO CONDUCT A PILOT STUDY AT ÅRDALSTANGEN HOMECARE

We are Nurses doing Global Knowledge at Høgskulen i Sogn og Fjordane Faculty of Teacher Education and Sport. As part of our examination in global knowledge, we are required to undertake a research project. Our research topic is **“Caring for the Family Members of Patients with Dementia in Homecare in Norway: A Nurse’s Perspective”**.

We write to request for permission to interview one of the nurses at the facility on Tuesday 6th March, 2012, in order to test our interview schedule.

If you need further details and clarifications, you can contact our supervisor Randi Jepsen at the Faculty of Health Studies on telephone number 57722577, email Randi.Jepsen@hisf.no

Your favourable response will be highly appreciated.

Bupe Simwanza, Regina Muchelenje and Nelia Langa