A SELF-MANAGEMENT PROGRAMME TO EMPOWER ADULTS SUFFERING FROM GOUT AND THEIR CAREGIVERS IN THE OMAHEKE REGION, NAMIBIA

A DISSERTATION SUBMITTED IN FULFILMENT

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Abstract

The prevalence of gout has increased over the last few decades. Of the 291 conditions studied in the Global Burden of Disease (GBD) (2010), gout ranked 138th for disability and 173rd for the overall burden of disability-adjusted life years. Statistics assume that in a population of 71,233 there are 200 people in the Omaheke region suffering from gout (Extrapolation of Prevalence Rate of Gout to Countries and Regions, 2015). This is evidence for a need to optimize management of the disease.

This study explores the experience of adults suffering from gout and of their caregivers in the Omaheke region, with the aim of developing a self-management programme to provide participants with education for diet and lifestyle changes for better management of their ill-health.

The researcher adopted a qualitative, phenomenological, exploratory, and descriptive approach. Two groups of participants (fourteen adults suffering from gout; and seven caregivers) were interviewed to learn their responses. Those suffering from gout were asked to report their experience of suffering from gout, and the caregivers were asked about their experiences of caring for their relatives. The research questions for those with gout and two caregivers were answered in unstructured individual in-depth interviews; five caregivers took part in a focus group discussion. Observations of the participants' reactions were also noted.

During Phase 1 of the research—a situation analysis—the phenomenological approach for collecting data from selected participants was used. The resultant inductive data analysis was used to develop a self-management programme.

During Phase 2, the conceptualization framework guided the development of a self-management programme, using the Practice Oriented Theory of Dickoff et al. (1968).

During Phase 3—the development of a self-management programme —an adapted version of three theories was used. The most prominent of these was the framework of the Chronic Disease Self-management Programme (CDSMP) which has shown

improvements in several areas. The Person-centered Care Theory—based on Carl Rogers's belief that the person is the expert concerning their needs, and Knowles's Adult Learner Theory in which the adult learner is seen as self-directed to learn, were theories used to inform the educational process.

In Phase 4, in a two-day training workshop the self-management programme was implemented and evaluated. Evaluation occurred immediately after every session and a summative evaluation at the end of the programme, to verify whether its interventions were likely to bring about the desired change among the participants. A programme outcomes evaluation was carried out three months after implementation of the programme.

Responses revealed great physical and psychological discomfort from gout, accompanied by disrupted sleep, decreased self-efficacy and social disconnectedness. Information was also seen as important for reducing predisposing factors and managing the illness, and recommendations were made for extending the impacts of the programme.

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Declaration

I, Maria Boraunyane Tibinyane, declare that this research report on "The self-management programme to empower adults suffering from gout and their caregivers in the Omaheke region" is a true reflection of my own research and that all the sources have been acknowledged in the document as also reflected in the reference list. The version of this work or part thereof is original, and has not been submitted before for any degree in this or any other institution of higher education.

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M B TIBINYANE

Acknowledgement

I know I will have missed some people out, who have been kind and helpful in my years of study, so what follows is by no means an exhaustive list of those to whom I am grateful. Please don't feel offended if I have missed you out as it is not a deliberate snub.

First and foremost, I would like to express my sincere gratitude to our heavenly Father who in spirit stood by my side and inspired me throughout my study programme during the setbacks and challenges of life.

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All participants who took part in this study, the adults suffering from gout and their caregivers for their co-operation and the contribution they made to realising this study.

This study came to fruition because of all of you. God bless you all.

Dedication

This study is dedicated to two gentlemen through whom I came to realize the degree of pain gout could cause. They are:

Mr. Benjamin T. Tibinyane
Mr. Patrick K. Mokwena
May their souls rest in eternal peace.

Below are figures that portray the intense pain adults suffering from gout are experiencing (Figure A 1.1: This is what gout feels like); and the development of gout (Figure A 1.2: The spiral of gout).

Figure A 1.1

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Figure A 1.2

Abbreviations

ADL	Activities of Daily Living
BC	Before Christ
CDL	Chronic Diseases of Lifestyle
CDSM	Chronic Disease Self-Management
CDSMP	Chronic Disease Self-management Programme
CCM	Chronic Care Model
CD	Chronic Disease
DALY's	Disability-Adjusted Life Years
FGD	Focus Group Discussion
GBD	Global Burden of Disease
HIS	Health Information System
HRQOL	Health-Related Quality of Life
IASP	International Association for the Study of Pain
ICF	International Classification of Functioning, Disability and Health
mmol/L	Millimoles per Liter
MoHSS	Ministry of Health and Social Services
NSAIDs	Non-steroidal anti-inflammatory drugs
SDL	Self-directed learning
SUA	Serum uric acid
TSSM	Theory of Symptom Self-Management
ULT	Urate-Lowering Therapy
WHO	World Health Organization
YLDs	Years of life lived with disability

CHAPTER 1: INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 Overview and Rationale

Gout is a common form of inflammatory arthritis—a condition that destroys joints, bones, muscles, cartilage and other connective tissues, hampering or halting physical movement. The condition is characterized by sudden and severe pain, redness and tenderness in the joints, most commonly in the base of the big toe. When affecting the big toe, gout can also be referred to as podagra (McIntosh, 2014). While most arthritis is chronic, gout is unique because it generally occurs in acute episodes. These attacks can happen over and over unless gout is treated. Over time, they can harm the joints, tendons, and other tissues (Arthritis Foundation, 2012).

However, gout isn't limited to the big toe; it can affect other joints including the feet, ankles, knees, hands, wrists, elbows and sometimes soft tissue and tendons. It usually affects only one joint at a time, but it can become chronic and, over time, affect several joints (Arthritis Foundation, 2012). Because they are the focus of all musculoskeletal movements, joints are prone to pain and stiffness as occurs in arthritis (Cooper, 2010).

The reason gout episodes often strike at night is that body temperature drops slightly during sleep, and this drop in temperature catalyzes the formation of uric acid crystals in the joint. This factor also helps explain why gout often affects joints in the feet and fingers - these extremities tend to maintain a lower temperature than the rest of the body. Additionally, when a body is sleeping and joints are at rest, some of the water in the joints' synovial fluid is reabsorbed into the body. The uric acid, however, remains in the joint. The high concentration of uric acid in the joint may spur the formation of uric acid crystals (Anbari, 2014).

Although the exact cause is still unknown, significant risk factors of gout have been identified. These include age, gender, obesity, purine-rich meat products and seafood, hyperlipidaemia, and drugs such as thiazine diuretics and low-dose aspirin (Roddy, 2014; Oh, Park, & Seo, 2011).

Hyperuricaemia is the underlying metabolic disorder that leads to gout. Serum uric acid (SUA) levels of >0.45 mmol/L define hyperuricaemia, the likely point of urate super saturation being 0.45 mmol/L at 37°C in a pH 7.4. Gout is the result of disturbed metabolism of purine, whereby uric acid levels in blood increase and mix with sodium urate in joints (Kumar, 2013).

Physiologically, uric acid, a toxic by-product of the digestion of protein, is usually exerted in the urine, but in gout it also accumulates in the joint fluid. The foreign substance accumulated in the joint spaces causes an inflammatory reaction. The substance can be eliminated fairly readily from the tissues which have a good blood supply, while in the joint spaces which are more isolated from the general circulatory system, their removal becomes more difficult (Kumar, 2013).

Although the clinical picture of gout includes some heterogeneity, the researchers identified four typical stages that describe the progression of the disease. The first stage of gout, which is of low gravity is the asymptomatic hyperuricaemia. At this stage the serum uric acid (SUA) levels are >0.45 mmol/L, without any outward symptoms. Urate crystals are deposited in tissue but cause only slight damage. The second stage is the acute gouty arthritis. This type occurs when the urate crystals that have been deposited in joint spaces, suddenly trigger an acute inflammatory process and intense pain, referred to as a "flare." Flares can sometimes be triggered by stressful events, alcohol and drugs. The third stage is the interval or intercritical gout. This gout refers to the periods or intervals in between attacks of acute gout. During this time, further urate crystals are being deposited in tissues. The fourth and advanced stage is chronic tophaceous gout. This stage is the most debilitating form of the disease. Permanent damage may have been dealt to joints and the kidneys. The patient can suffer from chronic arthritis and develop tophi—big lumps of urate crystals—in cooler areas of the body such as the joints of the fingers.

While gout affects both men and women, men are at a significantly higher risk than women. They are affected five times more often and at a younger age than women. While gout mostly occurs in men aged 40 and up, it usually affects women only after menopause. This is because of the effects that hormones have on the kidneys (Arthritis Foundation, 2012; Chen, Chuang, Wu, Yeh, & Pan, 2012; McIntosh, 2014; PubMed Health, 2015).

Researchers have a strong view that gout has become an epidemic. Gout is a common rheumatic disease which has recently drawn great research attention due to increasing incidence and prevalence reported worldwide in the past decades (Chen et al., 2012). Gout is increasingly recognized as a prevalent chronic disease state requiring appropriate long-term management while controlling for risk factors and co-morbid conditions (Graser, Pope, & Zychowicz, 2010). In China, for instance, whilst gout was traditionally regarded as a rare disease, in recent decades the prevalence of gout there has increased from 0.15 to 1.08%, which may be attributed to a shift in diet, lifestyle, and aging (Dai, Li, Li, Liu, Ou-Yang, Lu, Li, Li, Mo, Schumacher, & Zou, 2012).

According to Kumar (2013) gout, that was formerly considered a problem of the Western countries, is becoming increasingly international in scope as more and more countries report increasing incidence and prevalence rates of gout. Although no statistical data about the prevalence of gout in Namibia is available, similar increases in prevalence cannot be excluded. Many Namibians, both rich and poor, neglect looking after their health and have bad habits such as drinking too much alcohol, smoking, eating unhealthy food and not exercising, says local medical practitioner Dr. Susanna Horn ("High cholesterol", 2014).

Chronic non-communicable diseases, including gout, are largely due to preventable and modifiable risk factors such as high cholesterol, high blood pressure, obesity, physical inactivity, unhealthy diet, tobacco use and inappropriate use of alcohol. These factors result in various long-term diseases which account for high mortality rates due to various health complications (Setswe, Naudé, & Zungu, 2011). These health complications include stroke, heart attack, and other types of health problems. Rosenthal (2011) identifies these conditions as Chronic Diseases of Lifestyle (CDL). Whilst the non-modifiable risk factors— age, sex, race and genetics—are beyond the control of the individual, the modifiable risk factors can be changed through health education and health promotion strategies.

1.1.1 Context of the Study

The study participants were drawn from the Omaheke Region. The region is located in the eastern part of Namibia. It has a population of 71,233 and is known as cattle country, with a tradition of consuming large amounts of red meat. A notable event in the Omaheke region is the annual “Meat Festival” which draws visitors from all over the country and during which a great deal of red meat is consumed (Omaheke Region-Census Selected Indicators, 2001-2011). Figure 1.1 displays the map of Namibia of which the Omaheke region is part.

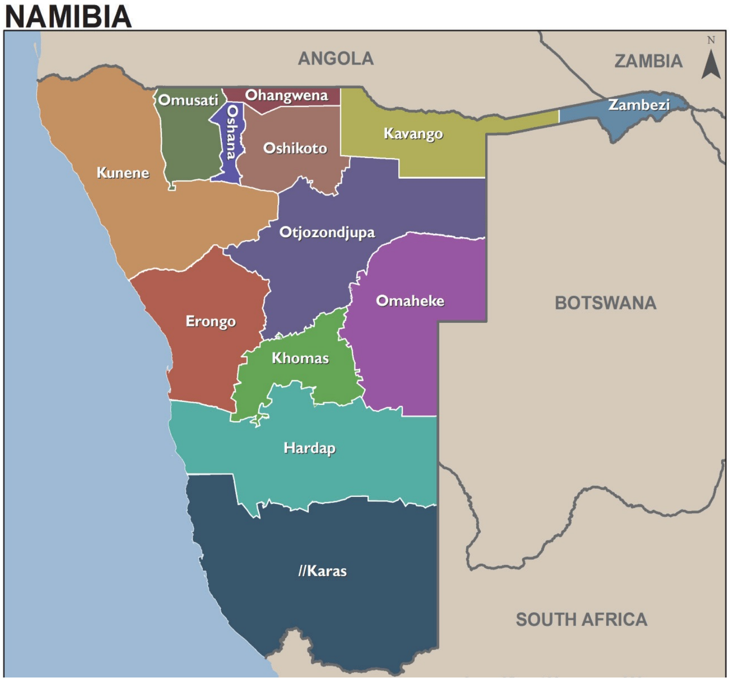

Figure 1.1: Map of Namibia

1.2 Problem Statement

Although Namibia health information system (HIS) does not make provision for statistics on gout, people are seen with noticeable signs of struggling with daily activities as a result from the condition. This situation is also observed by the researcher in the Omaheke region. The statement can be supported by the extrapolated statistics which assume that in a population of 71,233 there are 200 people in the Omaheke region suffering from gout (Extrapolation of Prevalence Rate of Gout to Countries and Regions, 2015).

As a community health nurse, the researcher sees this problem prevailing as more and more people are seen hopping along on one leg and cringing with pain. No matter what medical intervention they are receiving, their experiences of suffering from gout while being treated have not been documented before. Although these people are on treatment, they still display mobility disorders as well as co-morbidities like hypertension and diabetes. It is well-known that gout is affected by lifestyle as well as by genetic disposition. These elements can adversely affect the quality of life of these people. What is needed is not only medication but also a self-management programme to enhance their quality of life. To compile such a programme, it is necessary to obtain information about their experiences of living with gout.

The aforementioned statements are general and do not give a clear picture of the problem by regions, including the Omaheke region. Having said this and in view of statements such as “Namibia as a country of red meat-eaters, especially beef, has many Gout sufferers, just like there are sufferers in other parts of the world,” (Klassen, 2014), and “As much as Namibians love their red meat, the problem of these two diseases (gout and hypertension) intensifies” (Gaomas, 2007), it is clearly essential that these people be empowered through educational and counselling interventions to manage their ill-health and to lead an appropriate healthy life style. Researchers such as Chen et al. (2012), Dai et al. (2012) and Graser et al. (2010) have a strong view that gout has become a worldwide epidemic.

1.3 Purpose of the study

The purpose of this study is to explore and describe the experiences of adults suffering from gout and their caregivers in the Omaheke region, and to develop a self-management programme.

1.4 Objectives of the Study

- To explore and describe the experiences of adults in the Omaheke region who suffer from gout (Phase one)
- To explore and describe the experiences of caregivers who are taking care of adults suffering from gout (Phase one)
- To conceptualize the findings (Phase two)
- To develop a self-management programme (Phase three)
- To implement and evaluate the self-management programme (Phase four)

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1.5 Significance of the Study

Although considerable research has been devoted to the magnitude of the burden of chronic diseases, rather less attention has been paid to how an individual could deal daily with the condition (MoHSS, 2012).

As one gout sufferer observed: “In almost 20 years that I have suffered with gout, I have been offered many a cure by fellow sufferers and have realized that gout has no cure, but that it can only be kept at bay by committing oneself to a regimented and controlled diet” (Klassen, 2014).

The envisaged self-management gout programme will empower adults suffering from gout and gout related disorders to better control their situation.

1.6 Paradigmatic Perspectives

According to De Vos (2011) all research studies are conducted within a specific paradigm. Paradigms are an entire constellation of principles, values and techniques, a set of beliefs shared by a group of scientists about what the natural world is composed of, what counts as true and valid knowledge, and what sort of questions should be asked, and what sort of procedures should be followed to answer those questions (Haralambos & Holborn, 2013; Matthews & Ross, 2010).

Babbie and Mouton (2010) describe a paradigm as a model or framework for observation and understanding; it has an impact on what the researcher sees and understands. Again, paradigms are important for research, as they contain beliefs or assumptions that guide the research inquiry (Guba & Lincoln, 2005). In describing a paradigm, Neuman (2011) sees it as a general framework that includes basic assumptions, major questions to be answered, models of good research practice and theory, and finding answers to these questions.

1.6.1 Theoretical Influences

Philosophically, researchers make claims about what is knowledge (ontology), how we know it (epistemology), what values go into it (axiology), how we write about it (rhetoric), and the processes for studying it (methodology) (Creswell, 2009). Polit and Hungler (2014) describe assumptions as basic principles that are accepted as true on the basis of logic or reasoning, but without proof or verification, and Patidar (2013) also states that an assumption is basically a beliefs or idea that is held to be true; an act of faith which does not have empirical evidence to support it. A philosophical assumption is a conclusion based on one’s having a background and knowledge of a particular subject or discipline. When a philosophical assumption is made, a person uses their background knowledge of a subject to answer questions or make a decision using values and principles of that subject. Assumptions function as foundational beliefs or statements that support whatever decisions a researcher makes during the research process

In this study the assumptions as discussed below will form part of the researcher's terms of reference when developing the gout self-management programme.

1.6.1.1 Ontological Assumption

The ontological assumption relates to the nature of reality where multiple realities are embraced. Researchers embrace the idea of multiple realities and report on these multiple realities by exploring multiple forms of evidence from different individuals (Creswell, 2009). The assumption relates to the nature of reality and its characteristics such as social groups of people like the family, gender, ethnic group, institutions, and organizations; as well as social events, situations and social behaviour (Matthews & Ross, 2010).

In describing reality, Polit and Hungler (2014) view it as multiple, subjective and mentally constructed by individuals; thus reality arises out of each individual's perceptions of their experiences. Edmonds and Kennedy (2012) note that "reality" arises from each individual's perception of his or her experience, and Coady and Lehman (2016) are of the same opinion that reality is subjective and each individual's creation of reality is unique and independently formulated.

In this study the participants suffering from gout will each come with a different viewpoint and experience about gout and how it affects them in different ways, and the caregivers will respond in terms of how they have experienced caring for their relatives

1.6.1.2 Epistemological assumption

According to Creswell (2009; 2013) epistemology is about how we come to know the world about us and the different levels we aspire to achieve; the way of interpreting the world; the relationship between the knower and the known. Researchers try to get as close as possible to the participants being studied. Epistemology as a theory of knowledge presents a perspective on and justification of what can be regarded as knowledge (Matthews & Ross, 2010).

According to Polit and Beck (2012) an epistemological assumption questions the relationship between the enquirer and what is being studied, thus ensuring the forming of a link between the researcher and the research subject. Subjective evidence is assembled based on individual views from research conducted in the field. In-depth, face-to-face interviews with individual participants and focus group discussion with their support network will facilitate vigorous interaction with resultant scientific based findings.

1.6.1.3 Axiological assumption

A value is an idea shared by the people in society about what is good and bad, right and wrong, desirable and undesirable. Values shape the ideals and goals of a society (Popenoe, Cunningham, & Boult, 1997).

Something is real when it is constructed in the mind of a person involved in the situation (Creswell, 2009). A researcher makes their values and biases known in the study and actively reports them, as well as considering the value-laden nature of information gathered from the field. The descriptions of the experiences of those suffering from gout will demonstrate the degree of how the lives and values of the participants are influenced by the condition.

1.6.1.4 Rhetorical assumption

Comparing and contrasting two or more related subjects will aid in the development of the writing and make the report more persuasive. The rhetorical structure of one's paper is how one goes about persuading the reader that what you are saying is worthwhile. Detailed discussion and analysis of similarities and differences will further enlighten the readers and illuminate the point one wants to make (Young, 2013). A rhetorical assumption means that what the researcher reports is based on what is observed in the most objective way possible for the differences in the findings to be compared and contrasted.

This assumption examines the language and the writing approach of the researcher. The language of the qualitative researcher becomes personal, literary, and based on definitions that evolve during a study. The rhetorical style of the research report has a humanistic approach to interpret and describe the research results thoroughly. The extent of the experience of suffering from gout and what the participants try in order to alleviate or avoid the pain or discomfort may lead to the ideal self-management programme.

1.6.1.5 Methodological Assumptions

Methodological assumptions influence the researcher with regard to the research design and methods of the research. The assumptions reflect the researcher's view of the nature and structure of science and research in his/her discipline. According to Towell (2011) methodological assumptions form the basis of the research project; they provide guidelines to the researcher. The research design and methodology for this study will be discussed in Chapter 2.

1.7 Theoretical basis of the study

Swanson (2013) suggests that theories are formulated to explain, predict, and understand phenomena and, in many cases, to challenge and extend existing knowledge within the limits of critical bounding assumptions. The theoretical framework is the structure that can hold or support a theory of a research study. A theoretical framework consists of concepts and, together with their definitions and reference to relevant scholarly literature, existing theory that is used for one's particular study. The theoretical framework must demonstrate an understanding of theories and concepts that are relevant to the topic of the research paper and that relate to the broader areas of knowledge being considered.

In support of the above statement, Silverman (2010) defines theory as the relationship between the concepts relevant to the phenomenon, thereby providing a direction in terms of understanding the phenomenon and also serving as a basis for considering the way in which the new knowledge about the phenomenon may be organized.

With a view to developing a self-management programme for people suffering from gout and gout-related disorders; and a programme for their caregivers, the following theories and approaches were deemed appropriate, as will be discussed in the developmental phase (Chapter 5).

1.7.1 Practice-Oriented Theory

A conceptual framework of the findings will be developed within the framework of the six elements of the practice theory, as outlined by Dickoff, James and Wiedenbach (1968). Practice theory developed in response to a need to develop substantive theory as a meaningful foundation for the development of self-management programmes in relation to specific practice concepts (Chinn & Kramer, 2015). Dickoff et al. (1968) and Towell (2011) argue that theory must be developed with a goal in mind, and to this end there is a purpose in the way in which the theory is developed. All concepts will be classified according to the survey list of Dickoff et al. (1968) in order to determine the agent, the recipient, the context, the procedure, the dynamics and the terminus of the programme. Accordingly, the survey list will be adopted for the formulation of the researcher's reasoning map, as will be explained in Chapter 4.

The reasoning map of practice-orientated theory asks the following questions, and each will be discussed broadly in Chapter 4:

- Who or what performs the activity?
- Who or what is the recipient of the activity?
- In what context is the activity performed?
- What is the guiding procedure, technique or protocol of the activity?
- What are the dynamics for the activity—whether chemical, physical, biological, mechanical or psychological? (Dickoff et al., 1968).
- What is the terminus or end point or desired outcome of the activity?

1.7.2 Philosophy of Person-centred Care

This study makes use of the Person-centered Care Theory, which is a philosophy based on Carl Rogers's belief in a client-centered approach rather than simply on the opinion of the health caregiver. The person who is suffering is the expert in their own life history and needs, and the health caregiver is merely a facilitator (Rogers, 2009; Pickard & Rogers, 2012). The Rogerian model, in caring for older adults suffering from chronic conditions, emphasizes that they are not children to be guided and trained how to behave, but adults with a life history, formed opinions, habits of independence and preferred activities and ways of life. More discussion on this philosophy is discussed in the developmental phase, Chapter 5, Section 5.3.1.

1.7.3 Knowles' Adult Learning Theory - Andragogy

The features and characteristics of adult learners as seen from Knowles' 5 assumptions of self-concept, self-directedness, motivation to learn, life experience and readiness to learn (Knowles, Holton, & Swanson, 2015) were used as a basis for the development of the self-management programme in Chapter 5 of this study. The five assumptions are:

- Need to Know: Adults need to know the reason for learning.
- Experience: Adults draw upon their experiences to aid their learning.
- Self-Concept: Adults need to be responsible for their decisions on education, involvement in planning and evaluation of their instruction.
- Readiness: The learning readiness of adults is closely related to the assumption of new social roles.
- Orientation: As a person learns new knowledge, he or she wants to apply it immediately in problem solving.
- Motivation (added later): As a person matures, their motivation to learn comes from internal factors.

1.7.4 The Chronic Disease Self-management Programme (CDSMP) frameworks

The frameworks of the Chronic Disease Self-management Programme (CDSMP) have shown improvements in physical exercise, symptom management, self-efficacy, and self-reports of health of chronically ill patients after their participation in the programme (Kim & Youn, 2015).

Jonker, Comijs, Knipscheer and Knipscheer (2015) assert that the central aim of the CDSMP is to teach people to cope with multiple chronic diseases. The researcher anticipated change in health-related behaviours in adults suffering from gout and their caregivers after providing them with information on self-management techniques.

1.8 Definition of main concepts

Gout

Gout was first identified as early as 2640 BC by the ancient Egyptians. Hippocrates, the legendary Greek physician, referred to gout as the "unwalkable disease" in 5th century BC, and observed links between the condition and certain lifestyle areas (McIntosh, 2014).

Gout was called the 'disease of kings' because it mostly afflicted wealthy individuals, but the recent rise in gout cases shows that the disease does not discriminate. According to the Stuff website, formerly, only aristocrats could afford to indulge in expensive foods and drinks such as wine and meat which made them susceptible to the disease; hence the nickname 'disease of kings' (Managing the “disease of kings”, 2015).

Chronic disease

Chronic disease (CD) is a disease that persists over a long period, usually ≥ 6 months. The symptoms of chronic disease are sometimes less severe than those of the acute phase of the same disease. CD may be progressive, resulting in complete or partial disability, or even lead to death (Mosby's Medical Dictionary, 2009). Chronic diseases (CDs) require long-term therapy; the response to therapy is suboptimal and a return to a state of complete or pre-morbid normalcy is the exception, not the rule (McGraw-Hill Concise Dictionary of Modern Medicine, 2002).

Medical Dictionary for the Health Professions and Nursing (2012) defines CD as a disease of long duration. If a disease lasts for a long time or for a lifetime, it's considered a chronic disease. A person with a chronic disease needs to manage it and treat it constantly. Even if the condition is brought under control or reaches a state of normality, the tendency is still there for relapse and must always be addressed.

Pain

The International Association for the Study of Pain (IASP) defines pain as:

Unpleasant and/or distressing: Under normal circumstances one tries to avoid pain. If it occurs, one would want to do something about it, like taking pain killers or avoiding movements.

A sensory experience: When pain receptors in the body are stimulated, the pain stimulus is transferred along the peripheral nervous system into the spinal cord and up to the brain. This allows the body to react appropriately.

Pain is an emotional experience: Some people experience pain in the absence of any actual tissue damage or other clearly definable physical cause, but they do indeed feel the pain. Pain is whatever the person experiencing it says it is, existing whenever the experiencing person says it does.

Pain can be a warning signal: When the body has been damaged—for instance by gout, acute pain is experienced. Acute pain is a warning signal and lets the body know that if nothing is done, there is risk of damage, in this case, for example, to the ligaments.

Programme

Hornby (2010) defines a programme as a plan of actions that will be done that is organized into a set of instructions that control the operation or functions. A programme is a series or planned combination of activities or strategies, with a set of instructions designed to achieve specific goals and needs, both human and physical.

Strategies and programmes will, in the context of this study, focus on helping participants to modify problematic behaviours. It is also imperative to consider selecting an assessment tool which will measure or demonstrate the improvements made in the programme.

Self-management process

Ryan & Sawin (2009) assert that self-management in this use refers to (1) the process of self-management, (2) self-management intervention programmes, and (3) the description of outcomes gained by engaging in self-management practices.

While Richard & Shea (2011, p. 261) maintain that self-management refers to "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions"; as a process, self-management is a dynamic, interactive, and daily process in which individuals actively engage to manage a chronic illness. Accordingly, Bandy & Moore (2010) conclude that optimal self-management entails the ability of an individual to monitor the illness and to develop and use cognitive, behavioral strategies to maintain a satisfactory quality of life, and emotional strategies to regulate their emotions and resulting behaviours in ways that society considers acceptable. This includes how the individual copes with unmet wants or needs, perseveres when faced with obstacles, and sets goals for himself/herself.

Patient Empowerment

WHO (2009) defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health” and should be seen as both an individual and a community process. Four components have been reported as being fundamental to the process of patient empowerment: 1) understanding by the patient of his/her role; 2) acquisition by the patient of sufficient knowledge to be able to engage with their healthcare provider; 3) patient skills; and 4) the presence of a facilitating environment.

Based on these four components, empowerment can be defined as: A process in which people understand their role, are given the knowledge and skills by their healthcare provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation.

Caregiver

Videbeck (2010) stated that caregivers can be family members, friends, social workers or nurses, who according to Carter (2010) need to perform functions such as shopping, housecleaning, cooking, paying bills, giving medication, toileting, bathing, dressing and helping with eating.

In the context of this study, a caregiver refers to someone who performs duties which are fairly light, such as stopping every few days by the house of someone suffering from gout in order to tidy up, or living with such a person to provide constant assistance with a variety of tasks as identified by Carter (2010).

1.9 Chapter layout of the study

The chapters for this study will be structured with the view to develop a self-management programme to empower adults suffering from gout and their caregivers in the Omaheke region to better manage their health. The chapters are as follows:

Chapter 1: Introduction and overview of the study: overview and rationale.
Chapter 2: The research methodology.
Chapter 3: Research findings and literature control.
Chapter 4: The development of the conceptual framework.
Chapter 5: The development of a self-management programme.
Chapter 6: The implementation and evaluation of the self-management programme.
Chapter 7: Summary and conclusion of the study: identification of its limitations, and recommendations.

1.10 Summary

Chapter 1 gives an outline of the study: the introduction to and rationale for the study and the problem statement; the purpose of the study and its objectives are outlined as well. This chapter also contains the paradigmatic perspectives and the philosophical assumptions used in the study. In the following chapter the research methodology is discussed.

CHAPTER 2: RESEARCH DESIGN AND METHODOLOGY

2.1 Introduction and Rationale

While the first chapter provides an overview and rationale of the study and paradigmatic perspectives of the research, the aim of this chapter is to describe the research design and methodology that will be employed in conducting the research on the experience of adults suffering from gout in the Omaheke region, and the experience of their caregivers in taking care of them. This will facilitate the development of a self-management programme for these adults and their caregivers to take better control of their health.

2.2 Research Design

A research design is a plan or blueprint of how the researcher intends to conduct the research. It also refers to a set of logical arrangements from which the researchers can select one of their specific research goals. A research design focuses on the end product; formulates a research problem as a point of departure, and focuses on the logic of research (De Vos, Strydom, Fouche, & Delport, 2011). Research design is used to structure the research in such a way that all the parts of the research project—the samples or groups, measures, treatments or programmes and methods of assignments—complement one another with the purpose of addressing the central research questions.

A research design may be described as a set of guidelines and instructions used by a researcher to make appropriate decisions in relation to the research problem. A research design encompasses an outline that will achieve the research objective; it is an overall plan for gathering data in a research study (Babbie & Mouton, 2009; Burns & Grove, 2009).

For this study the researcher adopted a qualitative, phenomenological, exploratory, and descriptive approach which was contextual in nature, in order to gain a better understanding and to discover meaning in the experiences of adults suffering from gout in the Omaheke region (Burns & Grove, 2009) and their caregivers.

2.2.1 Qualitative design

Qualitative research design is a means of exploring and understanding the meaning that individuals or groups ascribe to a social or human problem. The process of research involves formulating questions and procedures, collecting data, typically collected in the participants' setting, inductive data analysis, building from particular to general themes, and the researcher providing an interpretation of the meaning of the data (Creswell, 2009). The approach aims at examining and understanding a phenomenon of which little is known, so as to gain more in-depth information (Polit & Beck, 2012; Silverman, 2010). According to Matthews & Ross (2010) qualitative research is primarily concerned with stories and accounts of events, including subjective understandings, feelings, opinions, and principles.

Qualitative interviewing aims to explore deep beneath the surface of superficial responses to obtain true meanings that individuals assign to events, and the complexity of their attitudes, behaviours and experiences (HealthKnowledge, 2011). For this study a qualitative design was chosen in order to obtain the participants' lived experiences as there was little information available about the experiences of adults suffering from gout in the Omaheke region, and of their caregivers in the provision of care.

2.2.2 Phenomenological approach

The purpose of a phenomenological study is to describe experiences as they are lived in phenomenological terms in order to capture the lived experiences of the study participants (Polit & Beck, 2012). As a process of learning and constructing the meaning of human experiences through intensive dialogue with the person living with the experience (LoBiondo-Wood & Haber, 2013) the phenomenological study enables the researcher to generate a description of a phenomenon of everyday experience (Holloway & Wheeler, 2010). On the other hand, Creswell (2009) and Lewis-Hickman (2015) see the design as a strategy of enquiry in which the researcher identifies the essence of human experiences about the phenomenon as described by the participants. A research design is the foundation and framework of a study and helps find answers to the proposed research questions (Maxwell, 2013; Miles, Huberman, & Saldana, 2014). The decision to use this type of design was based on its flexibility; it allows for more freedom during the interview to explore essences of others' experiences (Jacobs & Furgerson, 2012; Miles et al., 2014). Researchers may use many different techniques, but central to the heart of qualitative research is the desire to expose the human part of a story (Jacobs & Furgerson, 2012, p. 1).

This was the researcher’s motivation for choosing a design that allowed for personal expression of a lived experience by participants. Phenomenology was therefore used to study the experiences of people suffering from gout, as well as the experiences of the caregivers in terms of caring for these people.

2.2.3 Exploratory design

An exploratory design may be the first stage in a sequence of studies on a specific problem, during which new data are collected and new hypotheses are developed to explain these data in a field where previously not much research has been done (Neuman, 2011).

Exploratory research is conducted to investigate and gain insight into a situation by way of finding answers to an unsolved question (De Vos et al., 2011). This research approach is used when a researcher examines a new interest or when the subject of the investigation itself is relatively new. Polit and Beck (2012) define an exploratory research design as "a study that explores the dimensions of a phenomenon or that develops relationships between phenomena." An exploratory design for this study was appropriate because it gave the researcher the opportunity to investigate the relationship between phenomena (experiences of the gout sufferers and those of their caregivers). Exploratory designs are used to investigate and increase knowledge of the phenomenon under study. They are not intended for generalization to a large population, and they provide the basis for confirmatory studies (Burns & Grove, 2009). In this study the design was exploratory, as there was no prior research exploring the experiences of adults of suffering from gout as well as the experiences of the caregivers in the provision of care in Namibia.

2.2.4 Descriptive design

The purpose of a descriptive design is to provide a picture of situations as they naturally occur. With the use of a descriptive study design the researcher is able to obtain more information about the characteristics within a particular field of study and present it in a descriptive manner. They can be used in developing a theory or a programme, to identify problems in current practice, make judgments or determine what others are doing in similar situations (Burns & Grove, 2009). Polit and Beck (2012) define descriptive research as a study with the main objective of describing an accurate portrayal of the characteristics of persons or situations.

In this study the story telling of the participants about their experiences was descriptively presented. The researcher used the descriptive design whereby she observed, described, and documented the scenarios as they naturally occurred during the fieldwork.

2.2.5 Contextual design

According to Holloway and Wheeler (2010) the context study design refers to the environment and the conditions in which the study takes place, as well as the culture of the participants and location. Pequegnat, Stover and Boyce (2011) are of the opinion that a contextual study is the study where the phenomenon of interest is studied in terms of its immediate context. In addition, a contextual study explains people's experiences in relation to their cultural and economic backgrounds or the world which determines people's experiences, and their responses to illness and challenges (Burns & Grove, 2016).

Subsequently, if the researcher understands the context, she can locate the actions and perception of individuals and grasp the meaning that they communicate because in qualitative research, events and actions are studied as they occur in everyday life settings. The researcher acknowledges the context in which the research takes place in order to understand the surrounding dynamics and systems (De Vos, 2011). This makes it imperative for the researcher to be sensitive to the context of the research and immerse themselves in the setting and situations because both personal and social contexts are important.

The study was contextual in nature and the context of this study was the Omaheke region with selected health facilities namely, Otjinene Health Centre, Post 3, Metsweding and Epako clinics. Omaheke region is known as cattle country, and it is not uncommon for a meal there to consist solely of beef, whether roasted, boiled or dried into biltong. In essence, a meal without meat is not considered a meal. Simultaneous intake of soured milk is not excluded.

2.3 **Logic of Research and Reasoning Strategy**

Reasoning is thinking enlightened by logic. Logic is the laws of thought, idealized statements of how people reason (Darity, 2008). Logical reasoning is the process that uses arguments, statements, premises and axioms to define whether a statement is true or false, with the purpose of establishing whether the reasoning is true or false. Burns and Grove (2009) use logical reasoning to break the whole into parts that can be carefully examined, as can the relationships among the parts. Chinn and Kramer (2015) concur that this type of reasoning is a system of reasoning that deals with the form of relationships among propositions.

For the researcher to arrive at logical assumptions during this study, it is important to use knowledge to answer questions, solve problems and describe and explain phenomena by identifying and relating concepts, as well as by understanding, explaining, influencing and controlling propositions, variables and assumptions (Anderson, 2010) with the aim of validating the research findings.

The following established reasoning strategies will be discussed based on their application to this research study, and these will enable the formulation of logical arguments to assist with the exploration and description of the phenomenon under study.

2.3.1 Analysis

To analyze something requires taking a complex whole and separating it into its parts in order to examine and interpret it; the breaking apart of the whole will isolate the interrelated constructs that are relevant to the understanding of the main concept so that they can be interpreted (South African Oxford School Dictionary, 2009; Holloway & Wheeler, 2010).

Qualitative study as an ongoing process involves continual reflection about the data, asking analytic questions, and writing memos. Throughout the study, data analysis was conducted concurrently with gathering data, making interpretations and writing reports (Creswell, 2009).

2.3.2 Synthesis

Upon completing the process of analysis, synthesis takes place to combine the concepts that have been identified so that a whole can be formed. Thomas and Harden (2008) describe synthesis as the interpretation or explanation of data, while Walker and Advant (2010) describe it as the process of sifting out important factors and relationships and dividing concepts into categories or units that describe a phenomenon.

2.3.3 Deductive reasoning

Deductive reasoning proceeds from general premises to reach a particular situation or a specific conclusion (Burns & Grove, 2009). Sometimes this strategy is informally referred to as a “top-down” approach. Accordingly, deductive reasoning starts from the information that the researcher collects from themes and extractions from the entire experience.

De Vos et al. (2011) pointed out that deductive reasoning moves from the pattern that might be logically or theoretically expected to an observation that tests whether the expected pattern is actually occurring. A researcher begins by conceptualizing a theory about a topic of interest and then narrows that down to more specific hypotheses that can be tested. This process focusses even more narrowly when observations are collected to test the hypotheses. Deductive reasoning is used in research to confirm whether a researcher's assumptions are true or not for the purpose of the study (Babbie & Mouton, 2010).

2.3.4 Inductive reasoning

Inductive reasoning can be defined as moving from specific observation to broader or general concepts, whereby particular instances are observed and then combined into a larger whole or a general statement (Chinn & Cramer, 2015; Burns & Grove, 2016). It is also defined as a set of specific observations used to discover patterns that give some degree of order among events (Babbie, 2010). According to Polit and Beck (2012; 2017) inductive reasoning involves developing information from specific observations.

2.4 Research Methodology

A research method can be defined as a systematic procedure followed by a researcher, using a specific set of techniques such as interviews, observations and audio recording when collecting and analyzing data. Appropriate and effective research methods ensure that a research question is answered as reliably as possible, so that the objectives of the study may be achieved. It refers to the particular steps, advanced procedures and strategies used by a researcher when collecting and analyzing data during the research process (Creswell et al., 2011; Babbie & Mouton, 2009).

In this study, the researcher conducted individual in-depth interviews backed by a voice recorder to capture information that might be missed when recording observations in writing. For focus group discussion the same techniques were used.

The research method for this study was programme development and the study was conducted in four phases.

Phase 1: This phase involved a situational analysis.
Phase 2: This phase involved development of a conceptual framework
Phase 3: This phase involved the development of a self-management programme.
Phase 4: This phase involved the implementation and evaluation of the self-management programme.

Figure 2.1 displays the four phases of the research method that will be followed in the development of the self-management programme.

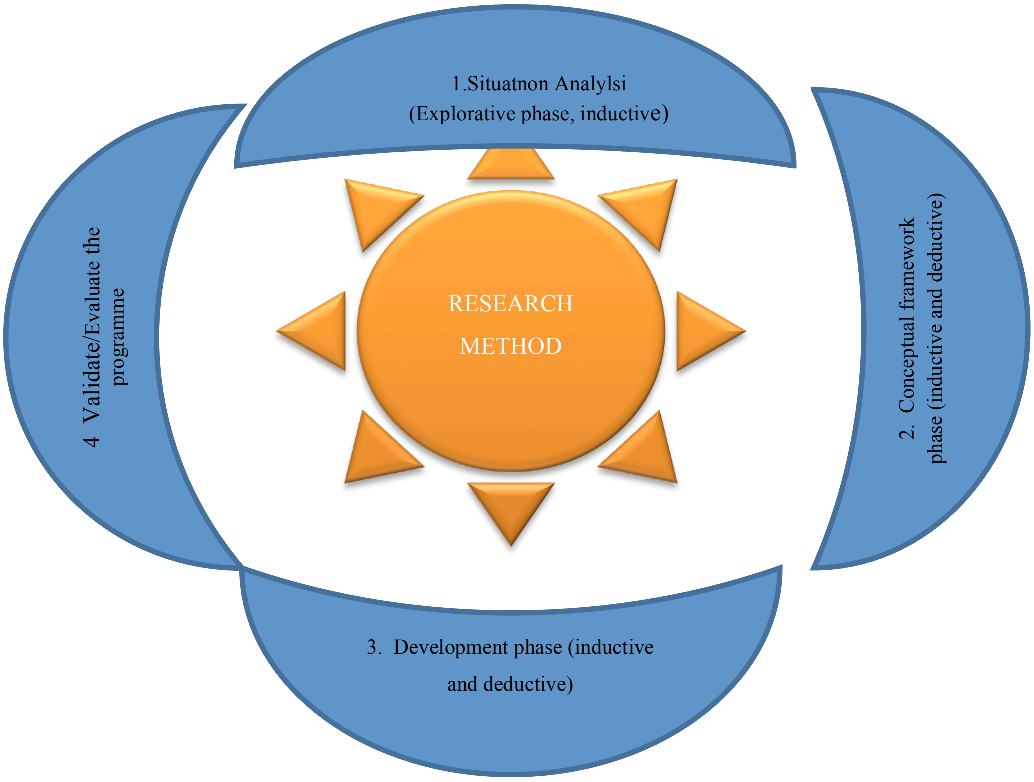


Figure 2.1: The four phases of the research method.

2.4.1 Phase 1: Situational Analysis

Description of perceptions of adults suffering from gout and of their caregivers.

Phase one was dealing with situational analysis and served as a starting step that explored and described the experiences of adults of suffering from gout in the Omaheke region, as well as their caregivers.

By means of phenomenological analysis, this step assisted the researcher to identify the essence of human experience about a phenomenon as described by adults suffering from gout and by their caregivers in their respective social environments. This phase involved a situational analysis from which the findings were used in the development of a conceptual framework.

2.4.1.1 Study Population

Polit and Beck (2012) define population as the entire set of individuals having some common characteristic. A study population refers to all members of a specific group of people who possess the attributes that the researcher aspires to study and about whom the researcher draws conclusions with regard to the findings of the study (Babbie & Mouton, 2010; De Vos et al., 2011).

The study had two study population groups. The first population was all adult patients diagnosed with gout for more than one year, who attended health facilities in Omaheke region, and the second population was their caregivers (a family member, life partner or a friend).

2.4.1.2 Sampling and sample

Brink (2010) tells us that sampling refers to the process of selecting the sample from a population in order to get information regarding a phenomenon in a way that represents the population of interest. Appropriate sampling enhances the transferability of the study results to a situation with a similar context. Polit and Beck (2012) define sampling as the process used to select a portion of the population to represent the entire population. By definition then, a sample is any subset of the elements of the population that is obtained for the purpose of being studied.

In a qualitative research study such as this, purposive sampling is the most powerful and preferred method of sampling. Purposive sampling was appropriate because the researcher could select the most eligible participants, those with an abundance of pertinent information (Welman, Kruger, & Mitchell, 2010), whereby as “a purposive, non-probability sampling the researcher purposely selected study subjects, based on personal judgment about which ones would be most representative”(Polit & Beck, 2012; Burns & Grove, 2009).

Purposive sampling is based on the judgment of the researcher regarding participants or objects that are typical or representative of the study phenomenon, or who are especially knowledgeable about the study at hand (Brink, Van Der Walt & Van Rensburg, 2012).

In this phase, three samples were determined, namely the health facilities, the adults suffering from gout and their caregivers. There are 13 health facilities in the Omaheke region and four (4) were purposively selected based on the density of their populations; these were Otjinene Health Centre, Post 3, Metsweding and Epako clinics. Purposive sampling of adults suffering from gout was then done using a list of their names, which was requested from the clinic staff.

2.4.1.3 Sampling Criteria

Participants should have similar characteristics in order to increase the theoretical understanding of the phenomenon being studied (Burns & Grove, 2016).

In this study the participants were chosen by means of purposive sampling. The rationale behind choosing this purposive sampling was because it was considered the most appropriate method to address the purpose of the study and because it was useful for exploratory study (Burns & Grove, 2009).

The sampling criteria facilitated the sampling process. The researcher used a non-probability purposive sampling technique to select the study subjects, and the selection of the participants was based on the following set of criteria:

- Population 1 consisted of fourteen (14) adults suffering from gout,
- Adults aged 20 years and above,
- Diagnosed with gout for longer than one year,
- Able to express themselves in English, Afrikaans or their vernacular, and
- Freely and voluntarily giving informed consent to be interviewed.

Sampling continued until the point of data saturation. According to Polit and Beck (2012) the proponents of qualitative research postulate that sample size is statistically insignificant in qualitative studies because, even if data is derived from only a few cases, sampling is based on data saturation. Data saturation was reached after fourteen (14) adults suffering from gout were interviewed to determine the sample size. Saturation, therefore, refers to the moment when the subjects' descriptions become repetitive, with no new or different ideas emerging during the data collection process (Fain, 2009; Rohde, 2010).

Because data analysis was inductive and ongoing, data saturation was used to determine the point at which no further interviews needed to take place. The interviews and any other data collected in this study were analyzed during the research process. Because of the goal for saturation, there was no formula to decide in advance the precise number of interviews that would be conducted.

In the final analysis Denzin (2012) noted that there is a direct link between data triangulation and data saturation; the one (data triangulation) ensures the other (data saturation). In other words, data triangulation is a method for arriving at data saturation.

- Population 2 comprised of seven (7) caregivers,
- Having stayed with their care-recipients for longer than one year,
- Able to express themselves in English, Afrikaans or their vernacular, and
- Freely and voluntarily giving informed consent to be interviewed.

Five (5) caregivers were sampled for focus group discussion, besides two (2) caregivers who were interviewed individually. See section 2.4.1.7.2 for the focus group discussion.

2.4.1.4 Preparation of the research field

According to Van der Waal (2017) field work in qualitative research is context-bound, whereby the researcher comes into direct contact with the participants in order to collect and analyse the data.

Upon obtaining permission from the Ministry of Health and Social Services (MoHSS) of Namibia to conduct the research at the health facilities, the researcher contacted the managers of the identified health facilities telephonically to obtain their permission in this regard. After identifying herself and explaining the purpose of the research study, arrangements were made for specific dates and times when the interviews could be conducted (Rubin & Babbie, 2010). The researcher used the opportunity to arrange for a peaceful and quiet venue where the interviews could be conducted. The researcher's request received a welcoming response as the managers knew her from their previous work relations.

A suitable room in each facility was arranged for interviewing the participants. The suitability would be characterized by an available, non-essential room (not required for use for alternative activities at the scheduled time of interviewing), in order to avoid interruptions and movement and ensure privacy. Other noise and visual distractions would also need to be limited, as well as a preference for adequate lighting, ventilation and seating, for comfort (Kloppers, 2012).

2.4.1.5 Data collection

Data collection is regarded as a process during which data relevant to a phenomenon is sourced through instruments such as interviews, questionnaires, observations, and field notes with the aim of providing possible answers to a research problem (Creswell, 2009).

Data collection involves setting boundaries for the study by identifying the sites and selecting subjects for gathering information through unstructured or semi-structured observations and unstructured individual in-depth interviews, documents and visual materials, as well as establishing the protocol for recording information from the participants in order to achieve the research objectives. In this study, the researcher was actively involved in the process of collecting data (Creswell, 2013; Burns & Grove, 2009) the goal of which was to obtain an authentic insight into the participants' experience. The data collection process consists of preparing the field, conducting the unstructured individual in-depth interviews intended to explore the experiences of the adults suffering from gout and their caregivers, focus group discussion and taking field notes.

2.4.1.6 Pilot testing

While Holloway and Wheeler (2010) maintain that there is no need to carry out a pilot study in a qualitative research project, since the approach is developmental, Sarantakos (2012) maintains that researchers should never start the main inquiry unless confident that it will be reliable, effective and free from errors.

A pilot study was therefore conducted prior to the main study in order to identify unforeseen problems and to assess the feasibility of the study (Brink, 2010). Two (2) adults suffering from gout would be chosen with the criteria of being able to speak English or Afrikaans or any vernacular, to be interviewed at the Katutura Health Centre to determine any misunderstanding of the questions that might occur during the interview and also to ensure representation in the main study. The following research question was posed: "Could you please tell me about your experience of suffering from gout?"

For the two (2) caregivers a guiding question was: "What are your experiences of living with and caring for your husband/relative who is suffering from gout?"

The pilot test revealed that participants attached different meanings and different interpretations of the concept “experience”. In this light, prior to the main interviews, the researcher gave a detailed explanation of the meaning of the word “experience” as used in the study in order for them to explain precisely what they go through with the phenomenon.

The following discussion is on methods of data collection using various data collection instrument during the conduction of the main research.

2.4.1.7 Methods of data collection

Methodological triangulation implies that the researcher may use several methods in different combinations in order to gain the most detailed picture of participants' experiences. Triangulation is a characteristic of qualitative design as it allows for multiple views of framing the problem, selecting research strategies and extending discourse across several fields of study. The data allows the researcher to extract emerging themes and to have them discussed in the caregivers’ focus groups. Triangulation is the way in which one explores different levels and perspectives of the same phenomenon. It is one method by which the validity of the study results are ensured. Triangulation requires comparison across data sets and adds validity to the findings. For example, field-notes from the observations can be compared with participants’ experiences described in the unstructured individual in-depth interviews as well as in the focus group discussion in HealthKnowledge (2011). The triangulation method was selected to enhance the trustworthiness of the data.

The triangulation method for data collection was employed in the study, using the following instruments:

Unstructured individual in-depth interviews (2.4.1.7.1) were conducted to collected data from fourteen (14) adults suffering from gout, and from two (2) caregivers of adults suffering from gout. In-depth interviews were more suitable to explore their experiences of suffering from this condition and the experiences of the caregiving (De Vos et al., 2011).

Focus group discussion (2.4.1.7.2) was conducted with caregivers to generate as many views, perceptions and experiences as possible of living with and caring for relatives suffering from gout (Creswell, Ebersohn, Eloff, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen, Plano, Clark, & van der Westhuizen, 2014).

The researcher personally conducted the unstructured individual in-depth interviews, starting each with the single open-ended central question: "Could you please tell me your experience of suffering from gout" which was followed by probing to encourage provision of more detailed information.

The caregivers were given a guiding question: "What are your experiences of living with and caring for relatives suffering from gout?" This was followed by probing with the intent to elicit different views and opinions from the participants.

Participants were kept informed throughout on the purpose and objectives of the study and the applicable procedures, and signed permission was obtained from the participants when they had consented to take part in the study (Burns & Grove, 2009). Anonymity refers to the assurance that participants would be interviewed in privacy, that their identity would be protected. The participants were also assured that they could withdraw at any time during the interview, if they so desired (Brink et al., 2012).

The usefulness of the audio recorder and its advantages were explained to all participants, after which some refused to be recorded. In such cases, the researcher decided to do the interview without the audio recorder for these participants so that they would feel free to express themselves fully. The measuring instrument should not constrain participants from saying what they want to say (Ritchie & Lewis, 2013) such as the use of an audio recorder which can make the participants feel vulnerable (De Vos et al., 2011).

Voice recording was done, however, with those participants who were willing and who gave signed permission for the use of an audio recorder. Brink et al. (2012) caution researchers that without high quality data collection techniques, the accuracy of the research conclusion can easily be challenged. In support of this, Holloway and Wheeler (2010) pointed out that the best form of recording interview data is by using the audio recorder to capture the exact words of the interview. On the other hand, the caregivers had no problem with being recorded.

The aim of taking fieldwork notes (2.4.1.9) is to remember what happened during the interviews, and to incorporate and correlate this information with the audio-recorded data in order to meet the requirement of trustworthiness. Field notes also serve as a supplement for the data that cannot be portrayed by audio-recorded interviews, for example, reporting of nonverbal communication, as well as a description of the immediate environment in which the participants found themselves during the interview (Amukugo, 2009). In this study the researcher made use of field notes which are discussed under 2.5.1.10.

Mouton (2013) supports the use of field notes, and emphasizes that it is imperative that a researcher documents the data collection process as accurately and in as much detail as possible in order to keep a historic record for other possible researchers. He also stressed that as a form of keeping quality assurance in a qualitative research, the researcher should keep track of his or her fieldwork as a form of quality control. Therefore, by keeping a detailed record of what transpired during the fieldwork process, the researcher constructs a historical record of the whole process to which he/she can refer later if necessary.

2.4.1.7.1 Unstructured individual in-depth interviews

Unstructured individual in-depth interviewing allows the participants to tell their own stories in their own words, with prompting by the interviewer. HealthKnowledge (2011) summarizes the objective of the unstructured interview as being, 'to elicit rich, detailed materials that can be used in qualitative analysis. Its objective is to find out what kind of things are happening rather than to determine the frequency of predetermined kinds of things that the researcher already believes can happen'.

In-depth interviews are held in order to understand the “emic” or insider view of a phenomenon, culture, social world or issue (Polit & Beck, 2012). Unstructured individual in-depth interviews were conducted with the participants with the aim of extrapolating a picture of the understanding they have of their life-world at a personal level. This type of interview is intended to probe the participant’s deepest and most subjective feelings. At its extreme it may elicit repressed feelings that even the participant did not know he or she had, or was not willing to admit even to him or herself.

Some of the adults suffering from gout were interviewed in their own homes, in which case a contextual approach was applied that, according to Burns and Grove (2009) explains people's experiences in relation to their cultural and economic backgrounds or the world, which determine people's experiences and their responses to illness and challenges. Where adults suffering from gout were interviewed in their own homes, they were even more comfortable, since the setting was familiar to them (Watson, 2011).

On the other hand, two (2) caregivers were also interviewed individually to understand their lived experiences of caring for clients who are chronically ill. Fusch and Ness (2015) advise that this would be appropriate if one were already conducting individual interviews with a small number of participants and one would like to get a group perspective about the phenomenon.

2.4.1.7.2 Focus group discussion (FGD)

Krueger and Casey (2015), Denzin and Lincoln (2011) define a focus group discussion (FGD) as a carefully planned discussion designed to obtain perceptions in a defined area of interest in a permissive and non-threatening environment. Further on, Aziz (2015) states that FGD is related to qualitative research used to provide researchers with data which are not obtainable through documentation or records. The focus group interview is a way to elicit multiple perspectives on a given topic and is therefore one way to reach data saturation if one has a pool of potential participants to draw from (Onwuegbuzie, Leech, & Collins, 2010).

This method drives research through *openness*, which is about receiving multiple perspectives about the meaning of truth in situations where the observer cannot be separated from the phenomenon (Nepomuceno & Porto, 2010). This concept is found in interpretive theory, in which the researcher operates thorough a belief in the diversity of peoples, cultures, and means of knowing and understanding.

For caregivers, focus group discussion was conducted with five (5) of them, which was in line with De Vos (2011) that a smaller group of four to six participants (composed of homogeneous persons) is preferable when the participants have a great deal to share but, in general, groups are composed of six to ten participants, so that the group is small enough for all members to talk and share their thoughts, and yet large enough to create a diverse group (Lasch, Marquis, Vigneux, Abetz, Arnould, & Bayliss, 2010; Onwuegbuzie et al., 2010).

The participants were selected because they all had certain characteristics in common that were related to the topic, namely of caring for people suffering from gout. Focus group interviews were chosen in order to obtain data directly from these participants because in this way good interaction with the group and free and adequate responses are ensured.

Below are the behavioral techniques outlined in table 2.1 that are required for building rapport in focus group discussion.

Table 2.1: Behavioral techniques for building rapport in focus groups

To foster a relaxed, positive atmosphere:	To establish mutual respect among researchers and group members
- Be friendly - Smile - Make eye contact with participants (if culturally appropriate) - Speak in a pleasant tone of voice	- Set rules at the beginning of the focus group - Have a humble attitude - Do not be patronizing, for example, by unnecessarily repeating everything

- Use relaxed body language - Incorporate humour where appropriate - Be patient and do not rush participants to respond	participants say or “talking down” to them - Do not scold or berate participants for the content of their responses or for personal characteristics - Do not allow any participants to berate others in the group - Do not coerce or cajole participants into responding to a question or responding in a certain way.

2.4.1.7.3 Ground rules for building rapport in focus groups

By laying ground rules, all parties will be much better positioned if participants are kind to one another during the focus group and if they respect one another’s privacy afterward. Therefore:

- Ask participants not to discuss details of the content of the discussion once they leave the focus group site.
- Ask participants to respect other group members’ privacy by not divulging what any participant says during the discussion or the identity of any individual present once they leave the focus group site. (Remind them that in the informed consent agreement, you have pledged not to disclose anything concerning their participation in the study with anyone other than the research team).
- Ask that participants speak one at a time, such as in turn according to seating, or in the order in which participants indicate having something to say.
- Speaking one at a time lets everyone hear and react to each contribution.

Ask participants to treat one another with respect by not doing anything that could cause another member of the group to feel uncomfortable, such as singling out an individual for criticism, name-calling, or making pejorative comments about any given contribution. All participants need to feel free to express their opinions without fear of being attacked by the group (Guest, Mack, Macqueen, Namey & Woodsong, 2012).

2.4.1.8 Communication techniques/approaches during data collection

Barker and Gaut (2011) assert that interpersonal attitudes and communication skills are regarded as important during interviews and focus group discussions in order to obtain the relevant information from the participants without harming them since there may be emotional issues involved such as dependency and helplessness due to deformities as seen in the fingers and wrists of some adults suffering from gout. Interpersonal attitudes and communication skills will be discussed separately below.

Interpersonal attitude: The word ‘attitude’ in this study refers to an orientation on the part of the researcher that communicates care to the participants. During the conversation there is a need to demonstrate warmth, caring and a non-judgmental understanding of the participants. Accordingly, the basic attitudes and skills adopted in this study include the following:

Congruence: If the tone of voice, body language and the words do not match, there is a risk of sending a conflicting message to participants on a subconscious level. Congruence therefore refers to the ability of the researcher, during the interview, to be aware of how to interact with the participants as well as the ability to communicate this to them (Schmid, 2016). This means that, during the interviews and the focus group discussion sessions, the researcher had to play her role in such a way that what she said to the participants and the way in which she spoke remained consistent. This consistency would help build the relationship of trust which would enable the participants to provide valid information, concepts and statements which could then be explored and used for the development of a gout self-management programme.

Acceptance: During the unstructured individual in-depth interviews and focus group discussions the researcher adopted an attitude of acceptance in order to avoid making any judgements, either covert or overt, in respect of the participants. No predetermined questions were asked, in order to remain as open and adaptable as possible to the interviewee's nature and priorities; during the unstructured individual in-depth interview the interviewer "went with the flow" (Valenzuela & Shrivastava, n.d.). Therefore, during conversations, the researcher did not either directly or indirectly indicate that answers were right or wrong—all answers were acceptable.

Communication techniques: Communication is a type of interaction between people presupposing the exchange of information (Kemerov & Kerimov as cited by Zeleyeva, 2015). Communication skills were used during the interviews to enhance the participants' self-expression in order to enrich the data collected (De Vos et al., 2011). The following are some facilitative communication techniques that can be used to smooth the progress of the interviews: choice of language and terminology, focusing, probing, silences, paraphrasing and clarifying, minimal verbal responses, non-verbal encouragement, summarizing and timing.

The language and terminology that the researcher used was simple and appropriate to both the culture of the participants and their level of education to explore their experiences of suffering from gout, as well as the perceptions and experiences of those who live with and care for relatives suffering from gout.

Focusing was used to direct the conversation between the participants and the researcher in such a way that the participants focused only on the question being asked or on the topic of discussion.

Probing refers to stimulating a participant to produce more information, to clarify and expand responses and explain meanings (Brink et al., 2012); it is a way of eliciting more useful information or seeking clarification (Polit & Beck, 2012) to indicate to the participant that his/her answer is on the right track but that more information is desired: "Tell me more...". Therefore, probing was used when the responses lacked sufficient information; alternatively, paraphrasing and clarifying statements were used to make a point clearer or easier to understand.

To clarify is "to make a point clearer or easy to understand" (The South African Oxford School Dictionary, 2009). This can be accomplished by repeating the answer, "Did I hear you correctly, did you say…?" Such repetition of answers can correct errors and assure both participant and the interviewer that the answer is recorded correctly. Paraphrasing was also used by the researcher in order to restate the participant's message in a simple way and using fewer words, but without adding new ideas to the message. These techniques are useful for reassuring participants that they have been heard and understood (Bolderston, 2012).

Silence indicates that the interviewer knows the participant has begun to answer and is waiting for him or her to finish. Interrupting could derail the train of thought. According to Bolderston (2012), if used with effective follow-up questions when necessary, such a pause can prompt additional information from most participants. The South African Oxford School Dictionary (2009) defines silence as the "absence of sound or talk".

Minimal verbal response is the use of as few words as possible at any point during a conversation, especially when a participant is no longer responding or responding minimally. Encouragement would be: "Okay, …?" "Hmm ..." or "Eh …, then…?"

Non-verbal encouragement encompasses gestures such as winking, smiling or nodding of the head, or even changing the sitting position to restore confidence in the participant that he or she was actively listened to during the interview.

Member checking or reflective summary is done as a "brief account of a process giving the main points of the discussion, sharing the themes with the participants and allow them to comment on their accuracy" (Bolderston, 2012). This is a preliminary interpretation when participants can check and correct meaning of the data provided. It is introduced by saying, "Can we conclude then that ...?" This must be done in a natural and genuinely warm way so that the participants do not perceive the researcher as monotonous or stilted.

Timing is also important, as the participants must be given sufficient opportunity to finish speaking before reflecting on the perceptions of the researcher. It is important to try to understand the participant's life experience and how it relates to the phenomenon being studied (Bolderston, 2012). In other words, a reasonable amount of time is allowed to elapse between the time the participants have finished speaking and the point at which the researcher makes a reflection. In this way, the participants are also given adequate time to hear the reflection.

2.4.1.9 Field notes

When observing a culture, setting, or social situation, field notes are created by the researcher to remember and record the behaviours, activities, events and other features of the setting being observed. Field notes are meant to be read by the researcher to produce meaning and an understanding of the culture, social situation or phenomenon being studied.

Field notes are written accounts of the things the researcher hears, sees, feels, experiences and thinks about in the course of the interview; they are unstructured observations that they are making in the field. (De Vos et al., 2011; Polit & Beck, 2012).

Field notes, just like the audio recording, are taken to complement any information missed during the face-to-face interview and the focus group discussion. The interviewer's interpretation of the interviewees' answers will be open to independent examination, because the primary research materials will be available for study by others (Polgar & Thomas, 2013).

The researcher took different kinds of field notes as advocated by their proponents to describe the social situations and interactions that occur in the field of research as will be seen below.

Observational notes.

In support of the interview, field notes consisted firstly of observational notes whereby the researcher writes down what he/she hears and sees in terms of events and conversations observed in naturalistic settings, including the participants' non-verbal responses and a description of events, derived from watching and listening (Polit & Beck, 2012; Creswell, 2013; De Vos, 2011). Focus was on what had happened on that particular day, who was interviewed and where the interview was conducted, in order to provide information about actions and context as completely and objectively as possible (Polit & Beck, 2012).

Methodological notes

Polit and Beck (2012) define methodological notes as "the researcher's notes about the methods used during data collection process"; for instance, a reminder about why probing questions during the in depth-interviews were essential and why they could be fruitful in the subsequent observations. Subsequently, these notes may provide both a summary of studies and a critique of the strengths and weaknesses of the methods used. Methodological notes were therefore essential for the researcher to reflect the strength and weakness of using the phenomenological in depth-interviews to collect data and non-verbal observation during observation.

Personal notes

Personal notes are also called reflective field notes. They are the researcher's personal thoughts, reactions and hunches concerning the participants' non-verbal responses (Creswell, 2013). According to Polit and Beck (2012) these are "written comments about the observer's own feelings during the research process." Reflective field notes include the observer's speculations, feelings, problems, ideas, hunches, impressions, prejudices, analyses, and plans for future inquiry, clarifications, syntheses, connections, and other ideas about what she is learning in the inquiry. The researcher took personal notes while conducting the interviews. Reflective field notes were therefore, the researcher's written comments on her own feelings, reactions, reflections, and experiences on the lived experiences of adults of suffering from gout and gout-related disorders (Polit & Beck, 2012).

Analytic notes and their syntheses

Polit and Beck (2012) define analytic notes as “notes detailing the researcher’s interpretations of observed behaviour.” Analyses and syntheses include the researcher’s speculations about what she is learning, the themes that are emerging, patterns that she may be seeing in participants’ experiences, connections between experiences, her new ideas, her interpretations of the meanings of events and people’s comments, etc. These may be short notes written during participation in an event, or afterward while reading through a particular descriptive field note; or they may be longer “analytic memos” which incorporate information from many descriptive and reflective field notes. Analyses and syntheses constitute the ongoing process of clarifying meaning and interpreting the information being gathered in light of the relationships being developed between the inquirer and other participants, in light of questions being asked, and in light of stories the inquirer wants to share with others about the inquiry. The analytic notes will assist the researcher in her effort to attach meaning to the observational notes and personal notes, as well as to formalize meaning into clusters of themes during analysis.

Documentary analysis

This research method involves the study of existing documents, either to understand their substantive content or to illuminate deeper meanings which may be revealed by their style and coverage (HealthKnowledge, 2011). Also, documentary sources contain added knowledge about the group being studied. They act as sensitizing devices and make researchers aware of important issues (Holloway & Wheeler, 2009). In accordance with HealthKnowledge (2011), Holloway and Wheeler (2009) researchers use documentary sources and records because they give information for situations that cannot be investigated by direct observation or questioning, e.g., private meetings or the death of a key person.

2.4.1.10 The data collection process

Data collection commenced once permission was obtained from the relevant authorities. The overall languages used for data collection were Afrikaans, Setswana, English and Otjiherero. The researcher translated the responses of the participants from Afrikaans, Setswana and Otjiherero into English during verification of data with the individual participants. Data captured in the voice recording and field notes was transcribed verbatim at a later stage.

2.4.1.11 Interview setting

In all four (4) health facilities, venues were conducive for quality data collection in terms of seating arrangement, lighting and absence of disruptions. The same principle was applied during focus group discussion. The ethical principles of the participants' right to privacy, anonymity and confidentiality were adhered to throughout the research study. The participants were ensured of the right to refuse to join in the study and the right to withdraw their participation at any time without prejudice (Burns & Grove, 2009).

For the interview process to progress smoothly, the researcher established rapport with participants that was maintained throughout the interview period. For the same purpose the researcher established the ground rules in order to regulate the smooth interaction of the participants in either a nondirective or a directive manner (De Vos, 2011). Furthermore, the interviewer briefed the participants about the whole process and encouraged them to participate actively. The researcher also urged them to express themselves without fear.

In this qualitative research study an interview guide was used as a data collection tool to enable the researcher to maintain consistency with questions during interviews, and not to miss out any questions that could ensure obtainment of the rich data (Ridenour & Newman, 2008). These researchers are in agreement with Matthews and Ross (2010) that the purpose of an interview guide is to help the interviewer to remember the points to cover.

Although the use of audio recording in the process of interviews is acceptable to many people, permission to record the voices of the participants must be obtained first (Matthews & Ross, 2010). During the interview, the researcher simultaneously observed both verbal and nonverbal behaviour. These observations about body language formed part of the field notes. The atmosphere was relaxed and enough time was allowed to allow each participant to answer questions in detail. Soon after the interview was over, the researcher and the particular participant listened to the audio recordings to check for audibility and completeness (Koelsch, 2013). This type of exercise is referred to as member checking or reflective summary to ascertain the validity of the data.

2.5 Ethical considerations

The study proposal was admitted to and approved by the Ethics Review Committee of the School of Nursing of the University of Namibia and Post Graduate Committee of the University of Namibia (UNAM). The Research and Ethical Committee of The Ministry of Health and Social Services of Namibia also approved of the proposal by giving permission to conduct the research study at their facilities.

2.5.1 Ethical aspects

Research ethics are central to all research involving human participants. May and Holmes (2012) present six (6) issues dominating the discussion of ethical considerations in research that involves human participants as outlined below. It is therefore imperative that all participants involved in the research study should be made aware of their ethical rights during the research process so they can exercise these (Andrews & Halcomb, 2009).

2.5.1.1 The right to self-determination

Burns and Grove (2009) maintain that the right to self-determination is based on the principle that people are capable of controlling their own lives and that they have the right to choose their own fate. Participants were informed that refusal to join in the study and to withdraw from their participation would not be held against them.

2.5.1.2 The right to privacy, anonymity and confidentiality

According to Burns and Grove (2009) privacy is the right of an individual to determine which private information will be made public and when, and to be assured of confidentiality by a declaration that the participants' names will be kept anonymous. The right to privacy, confidentiality and anonymity would therefore be maintained by using codes.

2.5.1.3 The right to protection from discomfort and harm

The literature recommends a strict observation of ethical principles in all research undertakings to protect the research participants from harm and risk, and that the benefits of the study should be positive for the participants. The overall goal of this study is to develop a self-management programme to assist the patients suffering from gout and gout-related disorders to manage their health situation.

2.6 Informed consent

The document is a mechanism for ensuring that people understand what it means to participate in a particular research study so that they can decide in a conscious, deliberate way whether they want to participate. Informed consent is one of the most important tools for ensuring respect for persons during research. To ensure that participants' rights are respected and acknowledged, there needs to be in place a written informed consent (Bryman, 2012) which outlines the above principles. Other aspects included in the consent were the research purpose and objectives, an explanation of the study and what would be involved for the participants, as well as the details of the researcher and how to contact the researcher should a participant have questions (Burns & Grove, 2009).

2.7 Principles of research ethics

Three core principles, originally articulated in the Belmont Report, form the universally accepted basis for research ethics involving human subjects: the principles of respect of persons, beneficence and justice. This research study deals with these three (3) main criteria that need to be adhered to by every researcher as discussed below.

2.7.1 Principle of respect for persons

Respect for persons requires a commitment to ensuring the autonomy of research participants, and, where autonomy may be diminished, to protect people from exploitation of their vulnerability. The dignity of all research participants must be respected. Adherence to this principle ensures that people will not be used simply as a means to achieve research objectives.

Respect for autonomy also takes into consideration self-determination, which is the basis of informed consent. The principle of respect for a person indicates that the person should be treated as an autonomous agent with the right to self-determination and freedom to participate or not to participate in the research (Burns & Grove, 2009). The purpose, objectives, and process of the study were fully explained to the participants with the purpose of enabling them to make an informed decision before giving their consent

2.7.2 Principle of non-maleficence and beneficence

This principle incorporates a commitment to minimizing the risks associated with research, including psychological and social risks, and maximizing the benefits that accrue to research participants. One should do good and above all no harm. The researcher made sure that there were no anticipated ill effects. Questions were formulated with caution to avoid any discomfort or feelings of inadequacy on their part. The benefits of the study were made clear to the participants by explaining about the envisaged self-management programme. Participants were also informed of their right not to answer questions that they were uncomfortable to answer.

2.7.3 Principle of justice

Justice calls for a commitment to ensuring a fair distribution of the risks and benefits resulting from the research. Those who take the burdens of research participation should share in the benefits of knowledge gained. Or, to put it another way, the people who are expected to benefit from the knowledge should be the ones who are asked to participate. The principle of justice refers to the participants’ right to fair selection and treatment (Munhall, 2011). Equally, justice implies that all citizens have an equal right to the goods distributed, regardless of what they have contributed or who they are (Butts & Rich, 2015). The researcher selected all participants with fairness for reasons directly related to the research problem and not because they were readily available or could be easily manipulated (Brink, 2010).

2.8 Trustworthiness

According to Brink (2010) trustworthiness in qualitative research has become an important concept because it allows researchers to describe the virtues of qualitative terms. Trustworthiness is the degree of confidence qualitative researchers have in their collected data, as assessed using the criteria of credibility (trust-value), dependability (consistency), conformability (neutrality) and transferability (applicability). Researchers want their findings to reflect the truth, so that they can make meaningful contributions to their field (Polit & Beck, 2012). Krefting (as cited in Towell (2011)) suggests that Guba's model for trustworthiness should be used as it is conceptually well developed. It is also appropriate to qualitative designs as it ensures rigour. In this section the researcher used the criteria of trustworthiness as outlined below:

2.8.1 Credibility (trust-value)

Polit and Beck (2012) define credibility as confidence in the "truth" of data and the interpretation thereof. It involves establishing that the results of the research are believable; it also depends more on the richness of the information gathered, rather than the amount of data gathered. This study has credibility in that there is what is termed "prolonged engagement" whereby the researcher will stay in the field until data saturation and the scope of data is adequately covered, thereby also establishing confidence. Bowen (2009) refers to the confidence one has in the truth of the findings of a study that could be established by complying with different methods, such as prolonged engagement and support. In-depth interviews, focus group discussions and audio recording further maintained this criterion. The researcher repeated what and how the participants replied to the questions of the interview, as well as replaying the audio recording. To further ensure credibility, the researcher talked to the participants before starting interview to familiarize them with what was expected in the interview.

2.8.2 Transferability (applicability)

This concept relates to the extent to which findings from the research can be generalized or applied to other contexts or settings (Neuman, 2011). Clear criteria for purposive sampling and a clear description of the sample as well as time sampling, allowed for transferability. Furthermore, the generality of the programme gave the research study transferability. The criterion was also maintained by the dense description of the research context, transactions and process that were observed during the inquiry, so as to provide another researcher with sufficient information to evaluate contextual similarity (Polit & Hungler, 2006; Anney, 2014). The researcher addressed the concept of transferability by providing sufficient information about the field work. Transferability was ensured through thick, descriptive, clear criteria when nominating the sample, as well as time sampling, and a clear description of the participants based on the intensive way in which the data were collected. Transferability was also ensured by giving rich description of the results as supported by direct quotations by participants in phase 1, the conceptual framework in phase 2, the self-management programme in phase 3, and the evaluation of the programme in phase 4.

2.8.3 Confirmability (neutrality)

The concept of confirmability implies that an inquiry is free of bias or is separated from the researcher's perspectives, thereby reflecting the traditional concept of objectivity (Diebel, 2008) as regards the phenomenon under study. In a qualitative study design, the data’s ability to confirm the general findings (themes) and lead to the implications (educational programme) is the criterion for confirmability (De Vos et al., 2011). In essence, confirmability refers to the degree to which the results could be confirmed. Confirmability guarantees that the findings, conclusion and recommendations are supported by data and that there is internal agreement between the investigator's interpretation and the actual evidence (Brink et al., 2012).

The complete research proposal was examined by the research committee of the Faculty of Health Sciences, and the researcher ensured the confirmability of research project by safe-keeping of the raw data, field notes and audio recording.

2.8.4 Dependability (consistency)

The concept of dependability refers to the consistency of research findings in a qualitative research study. According to Jooste (2010) dependability of qualitative data refers to the stability of data over time and conditions. All the techniques that apply to the strategy of the criterion of trustworthiness all indirectly impact on the strategy of dependability. The researcher is responsible for describing the changes that occur in the setting and how these changes affect the way a researcher approaches the study. The researcher kept records of all researched activities. De Vos et al., (2011) also regard dependability as an alternative to reliability as they consider the qualitative correlate of the traditional notion of reliability.

2.9 Measures to Ensure Trustworthiness

Below are the tables that reflect the four criteria that, according to Babbie and Mouton (2010) are important in guiding the researcher in maintaining the trustworthiness of the research process. These tables are portrayed below as Tables 2.2, 2.3, 2.4 and 2.5 each with its strategy, criteria and methods of application.

2.9.1 Credibility or Trust-value

Table 2.2: Criteria and application for credibility

Strategy	**Criteria**	**Methods of Application**
Credibility	Prolonged and varied field perception	Sufficient time was spent with participants, allowing for in-depth interviews and data saturation. Two different types of groups were engaged in the research study: • fourteen (14) individual interviews of the participants suffering from gout, and • two (2) individual interviews of caregivers, and a focus group discussion with caregivers. Duration of the interviews was ± 20 minutes and of focus group discussions, ± 40 minutes.
	Examination of the phenomenon under different circumstances	Data were collected at different health facilities Otjinene, Post 3, Metsweding and Epako. Some individual interviews were conducted in the participants' homes and others were conducted at the health facilities. Focus group discussion was conducted in a classroom
	Reflexivity (field journal)	The researcher constantly kept check of her biases and personal background, thereby reflecting on her values, behaviour and position with the participants, in order to avoid influencing their responses and her interpretations arrived at during her fieldwork. The researcher's background, interest and familiarity with the clinics were clearly indicated during her full participation in the research, i.e., in data collection, analysis and interpretation.
	Triangulation	Different data sources were used, namely, in-depth individual interviews and focus group discussion and the different kinds of field notes. A voice recorder was also used, where permitted, to capture such interviews. Documentary sources about the group being studied added knowledge about situations that could not be investigated by direct observation or questioning.
	Member checking	Participants were immediately debriefed to determine

	for data confirmation	whether they felt that the data were accurate. The tape recordings were replayed for the participants' confirmation. Participants were given an opportunity to correct misinterpretations and provide additional information.
	Peer group debriefing / examination	The University of Namibia and the Ministry of Health and Social Services of Namibia analysed the research proposal and approved it. Faculty seminars were continuously conducted and the proposal scrutinized. Different experts in the nursing research field, i.e., senior colleagues advanced in their own field of study and other researchers, were consulted to refine the data so that the account would resonate with people other than the researcher.
	Structural coherences	Data analysis process was based on Tesch's (1995) eight steps. The elements of theory and practice by Dickoff et al., (1968) were used.
	Referential adequacy	The researcher attended periodic seminars on doctoral programme at the University of Namibia before the commencement of the research process, thereby promoting her insight into the process. Audio recordings and field notes were used to record data, and verbatim transcripts resulted in adequate data that could be referred to when necessary.

In this study credibility was maintained through prolonged engagement, persistent observation, triangulation, referential adequacy, peer group debriefing and member checks.

2.9.2 Transferability or Applicability

Table 2.3: Criteria and application for transferability

Strategy	Criteria	Methods of Application
Transferability	Purposive sampling and sample	Criteria for the sample of adults suffering from gout and their caretakers in the Omaheke region were identified. Selection of participants from different cultures Age group of adults suffering from gout was 20 years and above, having suffered for longer than one year. The criterion for selection of their caretakers was having stayed with the adults suffering from gout for longer than one year. Ability to communicate in Afrikaans or English or their vernacular, and willingness to participate were criteria.
	Generalisation from sample to the target population	By using multiple cases and informants, data were collected until no newer information was available which tells that the data were saturated. The data saturation allows generalisation for the target population in this region.
	Dense description	Data about participants, research contents and settings were adequately portrayed, providing a clear database which allowed for transferability of the research study.

Transferability was ensured through thick, descriptive, and clear criteria when nominating the sample, as well as time sampling. A clear description of the participants based on the intensive way in which the data were collected guaranteed transferability. This took place in the same way as the way in which the researcher reported sufficient and precise information in response to inquiries or to the participants.

2.9.3 Dependability or Consistency

Table 2.4: Criteria and application for dependability

Strategy	Criteria	Methods of Application
	Investigative audit	Supervisors' guidance was intense. There was dense description of the methodology.

		Experts in the research field were consulted. Literature controls were also carried out.
	Dense description of the research methods	Nomination of the participant population, sample and sampling, data collection and analysis were clearly indicated.
	Triangulation	Individual interviews, group discussion and field notes were employed.
	Peer group debriefing/examination	Experts in the field were also used to critique and to comment.
	Code–recode procedure	The services of one internal and one external coders were employed.

Dependability was maintained through an external inquiries audit, a dense description of the research method, triangulation, peer examination and code–coding procedure (Babbie & Mouton, 2010). The researcher sent the notes which emerged from the interviews and the interpretations of these notes together with the tape recordings which were recorded during the interviews to supervisors to check whether the researcher adhered to acceptable standards in respect of the research process.

2.9.4 Confirmability or Neutrality

Table 2.5: Criteria and application for confirmability

Strategy	**Criteria**	**Methods of Application**
Confirmability	Confirmability audit	Tape-recording the data was done in the interest of descriptive validity and referential adequacy. Field notes, including observational data were made to ensure interpretive validity and to further strengthen triangulation. The researcher made use of an independent coder, who had experience in qualitative data analysis to compare, and code and analyse the data. The coded and reduced data were synthesised Themes and sub-themes and conceptual framework were developed.

Confirmability guarantees that the findings, conclusions and recommendations are supported by data and that there is internal agreement between the investigator's interpretation and the actual evidence (Brink et al., 2012). The research process was described by detailing the methodologies used; how the data were analyzed and how categories and themes were formed, thereby ensuring confirmability. The researcher therefore ensured the safekeeping of the tape recordings, field notes and written notes from the interviews to enable the supervisors to determine whether the conclusion and interpretation were in keeping with their sources and whether they were supported by the inquiries.

2.10 Data analysis

The data in qualitative research is non-numerical; usually it is in the form of written words or video or audio recordings and photographs. Analysis of data in qualitative studies involves an examination of text, rather than numbers that are considered in quantitative research (Brink et al., 2012). Polit and Beck (2017) define data analysis as "the systematic organization and synthesis of research data". Data analysis refers to a process of working with the data to describe, discuss, interpret, evaluate, and explain the data in terms of research questions or hypotheses of a research project (Matthews & Ross, 2010). Subsequent to the data analysis process, is the interpretation of the data and the construction of the meaning ascribed to the participants' experiences, with the researcher allowing the results of the data analysis to reflect an in-depth picture of the relationship within and among the various aspects of the problems identified (Burns & Grove, 2016; Holloway & Wheeler, 2010).

In this study the researcher used Tesch's approach of recording, transcribing, and coding as cited by Mamabolo (2009) to develop an organized system of data. Tesch's eight steps entail a process of breaking down, examining, comparing and categorizing the raw data. Typical of qualitative design, data collection, data recording and coding, identifying of themes and sub-themes, interpretation and report writing were done simultaneously. Audio-recorded information and notes were transcribed in order to identify main categories and then entered verbatim for text analysis. The researcher opted for this process because of its systematic approach and clear description.

In Table 2.6 below are the steps of data analysis by Tesch and their application to the study.

Table 2.6: Tesch's steps of data analysis and their application to the study

Tesch's steps of data analysis	**Application to the study**
1. Reading to make sense of the whole. All the transcripts were carefully read and notes were made by the researcher as some ideas came to mind. This step necessitates careful and repeated reading of the transcripts to create a framework within which individual pieces of data could be understood and to identify significant words and phrases.	The researcher repeatedly re-read the participants' descriptions of their experiences, and listened to the audio recordings several times in order to familiarize herself with the details of the interview and to get a sense thereof as a whole by breaking it into parts. From the field notes of the interview transcripts, the researcher was able to disregard predetermined answers and saw what the participants had to say, thereby enabling her to gain a sense of the participants' meanings .
2. Identifying main topics. Choose one of the shortest and most interesting interviews, go through it and identify main topics that emanate from the interview to find the underlying meaning.	The researcher focused on words and sentences that seemed relevant for the phenomenon under study. The data were analyzed by comparing them with other data and classifying them.
3. Clustering and labelling similar topics into columns of major topics, unique topics and additional topics.	This process was repeated for each interview transcript. The researcher wrote notes in the margins of the transcripts in order to explore the database. Topics with similar meanings were reorganized and clustered together in the column as key themes and sub-themes.
4. Assigning each topic a code simply by abbreviating them and writing the codes next to the appropriate segment to see whether new themes and codes emerge.	After arranging topics into columns, the researcher went back to the data by abbreviating the topics as codes and writing the codes next to the appropriate segment. The researcher was also mindful of new major themes and codes that could emerge. In the coding, the emphasis

	was on trustworthiness and credibility. Similar items were given the same codes to generate descriptions.
5. Seeking ways of reducing the total list of themes by grouping topics that relate to each other (refining the organizing system). Find the most descriptive wording for your topics and turn them into themes.	All topics that were grouped together were checked for coherence. Topics became key themes or sub-themes and relationships between topics were mapped with the purpose of grouping similar topics according to a particular theme. Therefore, coding generated a number of themes that appeared as major findings of this study that have been used as headings in the findings section.
6. Identifying names for themes with the aim of sorting and organizing the coded data into meaningful phenomena. Make a final decision on the abbreviation of each category and alphabetize these codes.	To arrive at the final set of themes and codes, the researcher referred to the data many times to confirm and validate the emerging patterns. Subsequently a final column with key themes and sub-themes was created.
7. Grouping the data that belong to the same theme in one place (final abbreviation of category) and performing a preliminary analysis.	Data reduction is a form of analysis that sharpens, sorts, focuses, discards and organizes data in such a way that final conclusions can be drawn and verified. The act of giving the same codes to the descriptions was in essence a way to reduce the data.
8. Crystallizing themes into concepts. Recoding the data if necessary	The researcher grouped the descriptions of the participants' experiences, feelings and ideas into clusters of phenomena to form key themes and subthemes in order to formulate meaningful concepts within the framework and objectives of this study. These themes were used to develop the programme.

2.11 Summary

In the above chapter the appropriate research design used for the qualitative study was discussed, which followed the statement of the overall purpose of this study and its objectives. Logic of research and the reasoning strategies were also discussed. Research methodology with all its techniques, processes and instruments were detailed. Ethical considerations, with all the aspects of informed consent and principles of research ethics were also touched on. Measures of trustworthiness were depicted in table form, as well as Tesch's steps of data analysis. In the following chapter the discussion of the findings is presented.

CHAPTER 3: DISCUSSION AND LITERATURE CONTROL

"Many women and men are of the opinion that those suffering from Gout are faking it…. Being a gout sufferer personally has had its painful ups and downs. What I can tell you from my experience is that it is not a laughing matter; although seeing a person hopping along on one leg and cringing with pain might appear comical to on-lookers, it is no joke. It is very real and it is so intense that a mere touch of a feather can cause excruciating pain that can send the toughest man crying like a baby… Gout does not discriminate and it surely does not use discretion when choosing its victims… It is as real as the air we breathe!" (Klassen, 2014).

3.1 Introduction

The previous chapter presented a comprehensive description of the research design and methodology used in conducting this study. A qualitative approach was used because it was relevant for investigating the lived experiences of the adults suffering from gout as well as the experiences of their caregivers in caring for them. The investigation involved probing into the lived experiences of these adults suffering from gout and how this impacts on their daily lives. In order to do this, the objectives guiding the conduct of the study were to explore and describe the experiences of adults suffering from gout in the Omaheke region and to explore and describe the experiences of their caregivers.

In this chapter the data analysis of the findings regarding the lived experiences of the two groups of participants and the literature control is discussed. The data that was collected as discussed in Chapter 2, the empirical phase, eventually resulted in key themes and sub-themes being identified, and these were used in the development of the self-management programme of this study. In this chapter the findings are presented in a narrative form, and the participants’ responses are quoted verbatim to support the findings.

The researcher also discusses the activities engaged in during the field visits, whilst the results obtained during data analysis is discussed under a general overview of the demographic characteristics of adults suffering from gout. Though the study is of qualitative nature, the researcher deemed it necessary to present their disease assessment so as to give a picture of the disease burden the participants are dealing with, which might also have a negative impact on their lives.

3.2 The Process of Creating Field Notes

Data was collected using in-depth interviews and audio recordings. For individual in-depth interviews, fourteen (14) adults suffering from gout and two (2) caregivers took part in the study; and five (5) caregivers were involved in focus group discussions. The collected data was analyzed using Tesch’s data analysis approach as discussed in Chapter 2.

During the field work, it was necessary for the researcher to work out her relationship to the field, to the members in the setting being observed and to her own way of seeing things (bracketing). Where interviews were conducted at the clinics, the relationship to the field was in a favourable position as the sister-in-charge of the clinic was acquainted with the researcher from the past work relationship. The setting and participants were well arranged. Likewise, in cases of interviews in homes, the same sister-in-charge of the clinic prepared the participants with the assistance of the community health workers.

To most participants, the researcher was well known, which facilitated the working relationship with them quite well, and their willingness to participate in the research study was enhanced by the knowledge that they could access the information on completion of the study. Two types of interviews were conducted. Unstructured interviews were held with adults suffering from gout, with the central question posed to every participant, “Could you please tell me about your experiences of suffering from gout?” For members of the caregivers in focus group interviews, a guiding question was, “What are your experiences of living with and caring for your relative who is suffering from gout?”

The representations of communications included direct verbatim quotations of verbal statements made, literal transcriptions of interviews and informal conversations, as well as paraphrases in the researcher’s own words if the researcher was unable to obtain the exact quotations. Significant statements and clauses linked to the study were extracted from the transcripts. These statements were reviewed and scrutinized to ensure they relate to the objectives of the study. Meanings were then formulated for the significant statements, which resulted in the isolation of themes and sub-themes.

Reflective field notes were kept to reflect the researcher’s personal account of what she was learning. These notes included speculations, feelings, hunches, impressions and syntheses about what she was learning in the inquiry.

3.3 General overview of the participants

The accessible population consisted of 21 participants. The participants were fourteen (14) adults suffering from gout, ten (10) males and four (4) females, with whom individual in-depth interviews were conducted. The total number of caregivers was five (5) for focus group discussions and two (2) for individual in-depth interviews, all of whom were females (Appendices E & F).

In a study conducted in the adult population of France, researchers Bardin et al. (2016) concluded that, in accordance with previous studies, the prevalence of gout was higher in men than in women and it increased with age, which confirms the role of aging and postmenopausal status in gout development. They further supported their findings by saying that one older study had determined the prevalence of gout in men living in Paris, and found a prevalence of 1.1% among men ages 35–39 years and 2.0% among men 40–44 years. Omaheke region has a population of 71, 233 (Omaheke Region-Census Selected Indicators, 2001-2011). Based on the extrapolated statistics it is assumed that there are 200 people suffering from gout in the Omaheke region (Statistics by Country for Gout, 2015).

Rock et al. (2013) and Stamp and Chapman (2013) pointed out that patients with gout frequently have multiple co-morbidities, including hypertension, cardiovascular disease (CVD), renal impairment, diabetes, obesity, hyperlipidemia and in a combination known as the metabolic syndrome. These co-morbidities and their treatment may have an effect on the development of gout and on the choice of therapeutic agent. Likewise, hyperuricaemia and gout may have an important role in the pathogenesis of the co-morbidity (Stamp & Chapman, 2013). These statements are further supported by Rock et al. (2013) as they explained that some of these co-morbidities, such as renal disease, can contribute to the pathogenesis of gout by elevating serum levels of uric acid; in other words, some co-morbidities may be a cause rather than an effect of elevated levels of uric acid. In other cases, however, the possibility has been raised that high uric acid levels or gout, or both, might contribute to the development of co-morbidities, possibly including hypertension, metabolic syndrome and atherosclerosis.

A number of epidemiological studies from a diverse range of countries suggest that gout has increased in prevalence over the last few decades, making it the most common inflammatory arthritis, particularly among men, and particularly among middle-aged adults. Gout usually occurs in men in their mid-40s. Men of this age group who have gout are often obese, have high blood pressure and unhealthy cholesterol levels, and drink large amounts of alcohol. It is the most prevalent inflammatory arthritis in men and is associated with impaired quality of life (Roddy & Choi, 2014).

3.4 Analysis of field notes and research findings

The researcher prepared the notes and analyzed them while still in the field. This preliminary analysis fostered self-reflection for understanding and meaning-making. It also revealed emergent themes. Identifying emergent themes while still in the field allowed the researcher to shift her attention in ways that can foster a more developed investigation of those themes.

3.4.1 Emergent Key Themes and Sub-themes

This section deals with the lived experiences of suffering from gout as expressed by adults—namely, holistic discomfort (physical and psychological), increased levels of dependency on others, and loss of social network. The experiences of caregivers in the provision of care revolved around negative feelings both physically and emotionally and a sense of social disconnectedness.

From the data analysis of interviews conducted with the adults suffering from gout, and the accompanying observations, three key themes were isolated and with the caregivers two key themes emerged. The key themes were then further layered into sub-themes (Streubert & Carpenter, 2007). These themes provided the fundamental structure of the findings of the research study and are presented together with their supporting sub-themes.

Each of these emergent themes is presented in detail using extracts from the participants' personal quotes in the context in which they were expressed to give more meaning to the impact of gout and of caregiving on their quality of life (QOL). The various sub-themes from the participants' key themes will be regarded as health challenges, as expressed by adults suffering from gout and the caregivers.

An overview of the key themes and sub-themes obtained from the perception of adults' experience of suffering from gout during the data gathering process are presented in Table 3.1 below:

Table 3.1: An overview of key themes and sub-themes identified by adults suffering from gout.

KEY THEMES	**SUB THEMES**
Key Theme 1: Participants experienced holistic (physical and psychological) discomfort	Participants experienced different aspects of discomfort such as: Sub-theme 1: Excruciating pain in different body parts Sub-theme 2: Emotional consequences of suffering from chronic pain Sub-theme 3: Despondency Sub-theme 4: Disrupted sleep pattern
Key Theme 2: Participants experienced increased levels of dependency on others	Physical impairment related to: Sub-theme 1: Activities of daily living Sub-theme 2: Instrumental activities of daily living

Key Theme 3: Participants experienced loss of social network	Loss of social network as evidenced by patterns of: Sub-theme 1: Isolation Sub-theme 2: Lifestyle changes Sub-theme 3: Role changes

The concepts in the key themes will first be clarified. The researcher will then provide a short discussion on participants' experiences under the supporting sub-themes followed by direct quotations from the participants, and supporting literature.

3.4.1.1 Theme 1: Participants experience holistic (physical and psychological) discomfort

The concept of holistic discomfort derives from the idea of holistic pain relief, which addresses both physical and psychological discomfort. The holistic discomfort as experienced by adults suffering from gout results from unrelenting pain which affects an individual's whole being. Pain is always both a physical and an emotional experience (Fogel, 2012) and emotions are physical experiences (Jacobs-Hendel, 2018).

When physical pain caused by gout is a problem, holistic pain relief supplements and techniques can ease discomfort and provide emotional health benefits (Silver, 2009-2018). From the perspective of holistic healing, it is important to address not only the gout condition and its' accompanying symptoms of pain, but also the emotional aspects that accompany them.

3.4.1.1.1 Sub-theme 1: Experiences of excruciating pain of the gout flare attack felt in different body parts.

Pain seems to be the central experience of gout. For many adults suffering from gout, the first and most unpleasant and distressing experience with the symptom of gout was excruciating pain at the affected joint, mostly the lower limbs which drives them crazy.

Supporting the above statement are the following accounts:

"Kaote e ka tla ka tshoganetso le ka ditlhabi tse di boitshegang, ((o kopela matlho a goga sefatlhogo)) iesh thobane ya gago, ha e se gaufi le wena, ((o tsikinya tlhogo)) mokgwa o mongwe fela, ke go tlola-tlola hela gore o goroge kwa ntlwaneng ya boithomelo." Participant 14

[Gout can come suddenly and with severe pain, ((closes eyes and frowns)), and if you don't have your crutches nearby, ((shakes head)) there is no way but to hop to the bathroom during an attack.]

"My rolstoel moet altyd byderhand wees, ((raak aan die rolstoel en trek dit nader aan hom)) wanneer die blerri ding my aanval ((hy skud sy kop terwyl hy gesig trek)), sien, ((hy raak aan sy regter knie met sy regter hand, terwyl hy na sy linker enkel met sy linker vinger wys)) albei my enkels is aangetas, daar is geen ander manier van beweeg nie." Participant 8

[I have to have my wheel chair ((touches the wheel chair and pull it nearer to him)) close to me during an attack ((shakes head and frowns)), as both my ankles ((touches the right knee with his right hand, as he points to the left ankle with his left finger)) are affected, and I cannot lean on any one.]

"Lefa setlha sa gago se sa a tlala, kgotsa e le gone o tshwang kwa ntlwaneng ya boithomelo setlhabi sebe setla, o tla iphitlhela o itotetse fa o leng teng. Kaote ga ena ditlhong ka nako nngwe ona le batho." Participant 14

[Even if you are not aware of a full bladder, or you have just been to the bathroom and the pain starts, you find yourself passing urine there where you are seated. Gout does not have a sense of shame even as sometimes you are with people.]

Pain is both a sensory and an emotional experience that is felt differently by everybody. Moreover, there is a difference between how you are confronted with pain and how you try to tolerate it (Brancatisano, 2016).

The statements given by adults suffering from gout show that the unexpectedness of the attacks of gout, more often than not catch them by surprise. It is also apparent that the severity of pain has the inclination to awaken the need to use the bathroom. Therefore, they need to have at all times their supporting equipment at hand.

- The affected joint, often a big toe, causes so much pain that the person cannot tolerate even a bed sheet resting on it. Adults suffering from gout compared the pain to a very fierce flame placed near the toe.

The following statements explain how participants experienced pain:

"Ke gore, ha monona o motona, o rurugile, ke tla gata ka mohama wa lonao. Batho ha ba mpona ke tsamaya ke sa rwala ditlhako ba ntshega, bone ba tsaya hela gore ke tshwaragane le metlae. Ga ke a tshwanelwa ke go amiwa ke sengwe, a ke dikobo kgotsa diaparo (.) ijooh le eseng hela, ke tla kua gore." Participant 12

[When the big toe is swollen stepping on the side of my foot is the only solution. People think I am a clown seeing me go about bare footed laughter; I can't have anything touching my toe like a sheet, clothes (.) Nothing at all, or I will scream terribly].

"Ha ele kaote ya menona ya dinao bogolo o motona, o kare o tshubiwa ka kgabo ya molelo, ke go raya ke re ga nkake waba wa rwala ditlhako le ha ele dikaushu." Participant 11

[When the toes are involved especially the big toe, you feel like a very fierce flame is placed near the toe, there is no way you can put your shoes on or even the socks].

"Fa ditlhabi di le mo mononeng, ke bona o ka dikgona, gona le fa dile mo mangolen kana dinoka kana go o gongwe, eish, ha o a gone, o mo mathateng ((o oba oba thlogo))." Participant 14

[Getting that pain in the toe I consider relatively tolerable, compared to if you've got it in your knees or hips or somewhere, eish, then my friend, you have a problem ((nodding head)).]

Pain is unpleasant and/or distressing, and under normal circumstances one tries to avoid it, sometimes by avoiding movements or positions that bring on pain or make it worse, or by limping to avoid pressure (Odendaal, 2010). When pain receptors in the body are stimulated, it allows the body to react appropriately—for instance, by staying put in your bed or chair and not wanting to move, or by preventing anything from touching your affected part (Odendaal, 2010).

- The person is an expert of the experience of pain. Therefore if adults suffering from gout say they have pain, they mean it. Pain is individualized experience which only the person who goes through it can tell. Some participants experience the pain as being constantly stabbed with tiny, hot knives and some like being bitten by a snake,

The following statements are evidence to this:

"Gout is nie 'n grap nie. Ek dink die enigste mense wat verstaan wat ek deurmaak is (.) my man en kinders. Ek word selfs gemerk dat ek lui is en winderig. Jy weet, dit voel of jy keer op keer gesteek word met fyn, warm messe of gepik word van 'n slang " Participant 7

[Gout flare is not a joke. I think the only people who understand what I am going through are (.) my husband and children. I am even labelled as being lazy and moody. You know, you feel you are being constantly stabbed with tiny, hot knives or being bitten by a snake,] *"Hey, otji ihamise omapanga uandje tjimaveripura kutja mbiraisa omurungu omuua uriri tjimbihino kuvango kukara punauo tjimavekaungurisa omavinu. Ami uina mbeveraera kutja aveja okundjiriangera. Nambano pemunika ajo mbiri menjando."* Participant 2

[Hey, it hurts when my pallies think I am just putting on a face when I do not want to join them in their drinking spree. ((Smiling)) I even told them not to visit for a drink. Now it appears that I am being funny.]

Pain is an emotional experience: Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does. Some people who are suffering pain get upset if anybody remarks that it is "not so bad" and indeed, it is really bad. They do indeed feel the pain; they become despondent and depressed, which makes their pain worse and in the end the pain dominates their lives (Odendaal, 2010).

Physically, each emotion contains a program that causes very specific physiological changes. According to Jacobs-Hendel (2018), when an emotion is triggered in your brain, it sends a series of impulses all over your brain and body.

- The nature of pain and the appearance of his fingers prevented one participant from executing the universally accepted gesture of shaking hands when meeting people. It is evident that people do not always comprehend that gout is a real disease, as one adult suffering from gout observed.

One participant lamented in the statement below:

"Gantsi ha baeng ba goroga gore tlhola, kana o tsenwa ke bobohi go sale kgale, ha o gopola gore mongwe wa bone o tla batla tumedisho ya lebogo ((o beela mabogo morago)). Ga kere motho o na le go thukutha lebogo ja yo mongwe, a sa itse gore wena o mo mathateng aa utlwalang jang ((o tshegela kwa godimo)). Participant 11

[When people are coming to visit, and they want to shake hands, you're frightened that they might just shake it vigorously or touch the sore place ((holding hands behind the back)).There is that tendency of shaking one's hand vigorously, not knowing what problems you are experiencing ((laughing out loud)).]

With physical pain, there is an obvious link between the psychological experience of pain and an awareness of a physical location in the body. If the pain seems to come from an elbow, or a toe, or a hip, strangely enough, we can feel the physical pain in that location even though most, but not all, of the processing is going on in the brain (Fogel, 2012).

- What people may regard as one of their most painful physical experiences is nothing compared to gout. The degree of pain as experienced by one adult suffering from gout is as if their innermost self was torn to pieces.

This participant summed it all up in a more apt statement:

"Let me tell you something, having had back surgery after a car accident, a broken ankle with an undiagnosed crack on top of my foot, none of those compares to the pain gout flares give me every day. Your innermost self is literally torn to pieces. I'd rather live the rest of my life with any other painful conditions." Participant 5

Pain is experienced differently by different people, and if someone's pain is unbearable their suffering is just as valid as mine with more recognized pain. Whether you're a wimp, or you manage pain chronically every day, it's something we all feel, some more so than others (Brancatisano, 2016).

Williams and Craig (2016) revised the International Association for the Study of Pain (IASP) of 1979 by defining the concept of pain as “a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components”.

Odendaal (2010) reviewed the definition by the International Association for the Study of Pain (IASP) as to what it means and implies. The types of experiences he noted, are that pain is an unpleasant and/or distressing experience; pain is a sensory experience and pain is an emotional experience.

There seems to be a linkage between the physical experience of pain and psychological experience of pain.

Gout has both physical and psychological ramifications (Marks, 2014). Its unrelenting pain causes a great deal of mental and physical suffering or discomfort. Physical pain has distinct biological and psychological components that effectively represent stimulus and response. The biology of pain is the signal transmitted through the central nervous system that “something is wrong.”

3.4.1.1.2 Sub-theme 2: Experiences of emotional consequences of suffering from chronic pain

- There was a clear expression from the adults suffering from gout as to how the extreme pain can overstrain their emotions to the extent of tearfulness. Culturally men should be strong emotionally in whatever situation, but gout pain, it seems has no respect for gender.

The following statements are evidence to this:

"Pomautiro uomihihamo mbi ejenene okuritjinda mena rohoni kutja ovanatje vandje avehendjimunu tjimeriri, momunu…ovarumendu kavezere okurira; ohoni kuuo. Kombunda omutjise tjiuahavere avejenene okundjimuna tjimeriri tjimunauo." Participant 3

[At the beginning of the problem when the pain started I used to contain myself out of embarrassment that my children should not see me crying, ((laughing)). You see men are not supposed to cry; it would disgrace them. Later when the disease would strike they were used to seeing me sobbing like them.]

"Ditlhabi tsa kaote ga se motshameko ((o tsikinya tlhogo a tswetse matlho okare di mo tshwere)) aitse kare o ka lela jaaka ngwana, ha di go tshwere ga o battle ope ha thoko ga gago, le bone ba lolwapa ba go tena, aitsane mme le bone wa ba tena go riana waitse." Participant 11

[Gout flare is not a joke ((shaking head with eyes closed, demonstrating the feeling of pain)). It can send you crying, sobbing like a small child, unbearable pain that causes you to cry and become mean with the loved ones as it makes them irritable.]

"Kana go thunya mo, o hetoga hela o nna selo, le gore o tshwaragane le eng ga o itlhaloganye, o ka bua dilo le gone kana osa ikutlwe, o bo o thubega ka selelo o sa tewa sepe." Participant 10

[When it gets that painful, you become something else to the point of not realizing what you are doing. You can talk of things that you yourself do not understand. Then you break into tears without any cause].

When people feel emotional pain, the same areas of the brain get activated as when people feel physical pain—the anterior insula and the anterior cingulate cortex, meaning that physical and emotional pain have similar neural signatures (Fogel, 2012).

In everyday life any emotional or physical discomfort pain can cause altered personality

- Participants experienced anger during a gout flare. They often directed this emotion towards someone, usually the closest people to them. They stated the following with regard to elevated depressive mood, anxiety and anger.

"Hierdie pyne kan so intens raak, so pynlik dat dit voel jy kan mal raak, jy vat styf aan enige ding rondom jou met tande gekners en in daardie tyd soek jy niemand rondom jou nie." Participant 8

[Pain can be so extreme, so painful as if you are losing your mind, holding on anything around you. At that moment you don't want anyone around you].

"Tjimuna tjaaveripura kutja ondjo jauo, aavezengi ouzeu mbui tjiuautu mena rokutja eevenjegua tjiveri punaami. Eeutu okutanaura ovikaro nokupindika." Participant 1

[As if it was their fault, they would keep clear of me when the episode started because I would not want anyone around me ((laughing)). I would just change and become angry and anxious.]

"My liewe familie kry swaar in daardie tyd wat ek in pyne is, asof dit hul fout is ((lag hardop)). Ek raak sommer iemand anders met wie jy eintlik nie geassoseer wil word nie." Participant 7

[My dear family has a hard time when I am in pain, as if it's their fault [laughs aloud]. I turn into someone different with whom you won't actually want to associate.]

"*Weet jy, gedurende die pyne is ek 'n baie kortstondige mens, en lelik ((skuddend buig sy* *haar kop)) Maar na die pyne raak ek weer so selfbewus van wat gebeur het, dan voel ek tog so sleg oor my gedrag, aan die einde is daar geen uitweg as om net om verskoning te vra nie.*" *Participant 8*

[Pain during and after the flare makes me short-tempered and nasty [bending head]. But after the pain attack, I become so self-conscious about my outburst at times, that I feel I have to apologize.]

A client who is subjected to pain will experience psychological and emotional challenges (Silver, 2009-2018). The psychology of pain is the interpretation or meaning we give to that pain signal—the internal self-talk and beliefs about it which then drive our emotional reactions (Marks, 2014).

This study aligns with a study on the association between chronic pain, depressive mood, chronic fatigue, and self-efficacy in people with spinal injury (Craig et al., 2013). Results indicated that participants with high levels of chronic pain had clinically elevated depressive mood, confusion, fatigue, anxiety and anger, low vigor, and poor self-efficacy. Furthermore, both chronic pain and a depressive mood were shown to contribute to chronic fatigue.

3.4.1.1.3 Sub-theme 3: Experiences of feelings of despondency

- Participants shared common experiences of feeling worthless and frustration with respect to their reduced functional abilities as related to their immobility status.

They verbalized their feelings of being powerless and hopeless as follows:

"Nako ha o batla go tswa mo bolaong, olemoga o kare noka le yone jaanong le yone e a gana, o ikutlwa o kare o kokothetswe jaanong mo bolaong. ((o oba tlhogo)) Iyoh! ke gore ha sehela se se simolotse mo dinaung le mo dinokeng, ga nkake ka ba ka loga maano ape, ka gore ga ke itse gore a ke tla kgona go tsweledisa se ke se nagantseng." Participant 13

[As soon as you take your foot off the bed you realize that the hip cannot carry you to where you wanted to go, and you immediately get stuck ((bows his head)). Hey, when the episodes are frequent in the feet and hip I can't make plans because I can't be sure that I will be well enough to carry out any activities.]

"You usually get the flares in bed and you just sit there with your leg in agony waiting for the pain to stop which is intense and you just can't handle. With pain elsewhere, getting out of bed and hobbling around does eventually ease it, (.) but having it in the toe or knee, there is no way you can do it." Participant 6

Patients with a chronic illness often feel powerless, especially during the phase of diagnosis and early treatment. Patients realize that a chronic illness will dictate much of their course in life and that they have less control over what is happening to their body (Dewit, Stromberg, & Dallred, 2016).

The state of being despondent is denoted as depression of spirits from loss of courage or hope; sadness or gloominess (Thesaurus, n.d.). Feelings of emptiness, a lack of meaning or purpose are experienced by most people at some point in life. Others experience chronic feelings of emptiness, feelings of emotional numbness or despair.

- Living alone with no one to call for help when the gout pain strikes, was worrying just as not being connected to the outside world because of the inability to even move to the window to get a glimpse of what is happening outside.

The following statements are evidence to this:

"Ah, I have to keep my crutches by the bed so that I can get to the bathroom as fast as I can if need be. I live alone and I am worried ((opening eyes wide and shaking head))… when am I going to get the next flare up? Participant 5

"Hee, ditlhabi mo magwejaneng di nkitsa go tswa mo bolaong, mme le ha kere ke leka go atamela seokomela bagwe, kgotsa le ha kere ke dulanyana mo situlong, mma weee mathata a matonna le ha ke batla go ya ntlung ya boithomelo, gone ebile ke tswaralala hela ka dikeledi, ke sena ditlhong dipe mo go nna. ((O tsikinya tlhogo ka setshego))." Participant 11

[Hoo, the pain in both my ankles makes me unable to get out of bed as I dare not move, just to go near the window or sit on the chair, or worse still, to go to the rest room, then I burst into tears, without being ashamed ((shaking head)).]

Our moods are not only a function of what happens to us, but also of how we view the events in our lives and the meanings we assign to them. A sudden change in life circumstances may also produce such feelings. Pain does not just affect the body, it also affects how people feel emotionally. People can experience many losses because of pain, which sometimes leads to loss of confidence and low self-esteem (Healthtalk, 2014).

Chronic pain is often accompanied by feelings of hopelessness, depression and anxiety. One logical reason for this: studies have found that the more anxious and stressed people are, the more tense and constricted their muscles are, over time causing the muscles to become fatigued and inefficient for a person to move freely (Babbel 2010).

- The researcher observed that they walked more slowly and with shorter steps and stride lengths; with visible discomfort, limping with every step, a reminder of the daily struggle with this chronic condition.

To being slow in their daily work two participants, small shop owners stated:

"Eish, seemo se, se a tlhobaetsa, le go tsenwa o ka tsenwa ((o a hema)) gobone ga nkake wa diha sepe se o batlang go se diha, le ha ebile gole motlhohu jang, kutlo botlhoko e tsena thata ha menona le magwejana a rurugile jaaka jaana. ((o kaya jaaka a rurugile)). A o bona o tsentse mogopolo mo go diheng sengwe, mmele o bo o gana. Ditlhabi di ka mmele jaana o kare o tlhabilwe ka ente yo gotweng a tsose ditlhabi, shuu. O nna o ntse hela, go sena le haele sepe se o tla se dihang, ((o kaya maoto)) le maoto tota ga nkake wa tsikinyegela gope, nako ewa, ka re ke keledi hela e tabogang." Participant 12

[Eish, the situation is very devastating and frustrating mentally ((sighs)) because I'm not able to do what I want to, even if it is urgent, especially with both my toes and ankles all swollen like now (pointing at the swollen areas). Although my mind is set on something my body refuses to cooperate. The pain goes through my whole body as if every joint is affected, preventing me from doing my intended activities, shuu! You're bored to tears sitting there not being able to move your foot ((pointing at the feet)).]

"Ek het 'n winkeltjie by die huis ((hy wys in die rigting van die huis))*, maar die manier hoe hierdie pyn my ophou, dat ek nie eens kan beweeg nie, dink ek soms dit sou sekerlik beter was as ek nie 'n pynlike been gehad het nie, want dan kan ek baie beter my besigheid bestuur het. Ek stuur soms my dogter om geld te gaan trek om groceries vir die winkel te koop". Participant 8*

[I have a small shop at my house ((pointing in the direction of the shop)) but the pain keeps on throbbing for days and days and I can't even move, at the end you feel like you are better off without a leg, that without the troubling leg you could move around and manage your business. Sometimes I send my daughter to withdraw money to buy groceries for the shop].

Participants reported high levels of foot pain and disability, and experience difficulty in carrying out recreational and daily living activities requiring normal lower limb function. The ability to walk and move about freely is a central component to daily mobility. Gout in the toes or the hip joint leading to malfunction, the effect will be immobility which can be compounded by involvement of other joints in the leg.

A decreased self-efficacy affects people's psychological status and emotional reaction negatively in handling daily tasks or situations (Cherry, 2010; Clark & Becker as cited by Htay, 2010).

3.4.1.1.4 Sub-theme 4: Experiences of disruptive sleep pattern

- In this study participants reported sleep disruption, with problems of falling asleep and staying asleep and with gout flares from nowhere waking them up, and keeping them awake never to fall asleep again.

The following quotations from different participants highlight the sleep problems:

"Ha e kare o robetse mme ga wa thulamela, wabo o heta o raga kobo, mma weee, nako ewa o kubugetse ruri (o gotolola matlho)." Participant 12

[When you're half asleep, and you accidently touch the sheet, you are instantly wide awake ((open eyes wide)).]

"Hijenene okurara outuku auhe. Mbirara metanauka outuku auhe." Participant 4

"You can't turn over like a person normally does ((moving body)), I first have to sit up and move myself carefully onto the other side."

"You can't sleep continuously when it flares up, you experience brief episodes of awakenings, and you just can't sleep ((shaking head))." Participant 5

"I cannot sleep uninterrupted. I toss from side to side. During flares you can be awake all the time day and night…without even closing an eye ((clicking tongue))." Participant 6

Numerous studies find that sleep disturbance is one of the most prevalent problems in patients with chronic pain. Sleep is important for maintaining homeostasis and optimizing functions throughout the body. Humans require both pain and sleep for survival; however, chronic impairments in the systems regulating pain and sleep can have a broad negative impact on health and well-being.

- The researcher also noted that participants had improvised some strategies of coping with sleep disturbance. They would rather sleep uncomfortably so as not to sleep fast, afraid they accidentally rub their toe or ankle against a sheet. In this way they are able to sleep longer.

The statements below attest to this:

"((O gogile sehatlhogo)) ga nkake ka lala ke apere kobo mo dinaung,ka moo ga ke a tshwanelwa ke go amiwa ke sengwe mo dinaong, ke robala dinao tsame di le kwa ntle ga dikobo, eseng jalo, go raya gore ke tlaa kubuga le go tlola-tlola." Participant 11

[((Frowning)) I can't even have the sheet touching my feet and therefore I sleep with my feet uncovered or else I will wake up jumping.]

"Oh, oh, ongurova imue mbarara motjihavero mena romihihamo mbiavikotoka pehi tjimbararere munda umue." Participant 3

[Oh, oh, one night I had to sleep on a chair as I felt the pain was a bit less when I was sleeping in an uncomfortable position.]

"Hey, omihihamo vikuhisa ozombotu, mena rokutja utira okunjinjinga. Opumbi kondja okurara momunda kaani uriri." Participant 1

[Hey, pain limits my ability to have a good night sleep, afraid that you might just make a wrong movement. So I have to sleep in a certain way.]

Research has demonstrated that disrupted sleep will, in turn, exacerbate chronic pain. Thus, a vicious cycle develops in which the chronic pain disrupts one's sleep, and lack of sleep makes the pain worse, which in turn makes sleeping more difficult, etc. (Schrimpf, Liegl, Boeckle, Leitner, Geisler & Pieh, 2015).

3.4.1.2 Theme 2: Participants experienced increased levels of dependency on others due to physical impairment

Patients who were dependent on others for help with every aspect of their daily living or receiving care from someone else remarked on their dependency and sense of being a burden to others. Receiving care is not simply a matter of benefiting from others' help; it can generate feelings that one is creating physical, emotional, social, and economic hardships for one's family, without seeing an opportunity to restore the balance between receiving and giving; the result is a reduction in the care recipients' sense of self-worth or value (Tang, Hsieh, Chiang, Chen, Chang, Chou & Hou 2016). According to Singh (2009) acute and chronic gouty arthritis lead to significant pain, activity limitation and disability and impact patient’s health-related quality of life (HRQoL).

The perception of burden is understood to arise from a mistaken idea that the self is now useless; hence the person can offer nothing to others, and thus is burden (Gorvin & Brown, 2012). McPherson, Wilson and Murray (as cited by Gorvin & Brown, 2012) state that “The phenomenon, generally termed ‘self-perceived burden’ has been defined as: ‘empathic concern' engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility and diminished sense of self."

The physically ill who may need help in order to survive could be especially vulnerable to experiencing this sense of being a burden to others.

Physical impairment relates to:

- Activities of daily living
- Instrumental activities of daily living.

People typically need assistance for IADLs before they need them for ADLs. Many people will lose the ability to prepare food, but can still feed themselves, or they may be able to dress themselves, but no longer can get down the stairs to do laundry.

3.4.1.2.1 Sub-theme 1: Experiences of inability to execute fundamental activities of daily living.

- Participants displayed noticeable frustration when describing their experiences of not being able to execute even the easiest activities. They were tormented by the realization that they were dependent on family members due to gout, and this left them with feelings of guilt.

Participants expressed themselves as follows:

"Gantsi thata ke ikaegile mo go mme wa aka le babange fela go dira sengwenyana se se sa thusing sepe, jaanong tshe tshotlhe di dira gore ke seka ka ikutlwa sentle." ((O tsikinya tlhogo)). Og, ruri ke a tshwenyega e ele go ikaega mo go mme wa aka le losika lawame sebakeng sa bogole jwame." Participant 12

[Most of the time I depend on my family and others for simple things and that makes me to feel guilty ((shaking head)). Og, I am really concerned over being dependent on my wife and family because of my limitations].

"When I am really in pain, [closing eyes and bowing the head] I at times feel as if my whole family is also in pain, hanging around and not wanting to go anywhere. Shu! I'm a liability to my family because they never know what to expect as the disease can come unexpectedly". Participant 6

"Ouzeu tjinene okunjinganjinga tjiuri mongaro ombi ndjo. Ongaro ndjo ikara punaami omajuva kaani otjirimuna tjimuna uapandekua. Otjiuso kuhiruo vikuria, nokuvaterua novina mbimohepa. Participant 4

[It is very hard to move around during a flare. It stays with me for a while to several days, keeping you hostage. So you have to be waited on for food and almost everything you need]

Activities of daily living (ADL) are routine activities that people tend to do every day without needing assistance. There are instances that adults suffering from gout are not able to perform without assistance two, or sometimes three, of the six basic activities of daily living (Farlex Partner Medical Dictionary, 2012; Stamm, Pieber, Crevenna, & Dorner 2016).

- Some reported not being able to go to the bathroom, or to clean themselves after toilet use. They have regressed to their innocent, painfree infancy or toddler phase, they reminisce. But this time the phase is painful.

"Mehepo mbatero tjimerihuikike poo tjimehukuro zombanda tjimuno ozomburukova, ovikausina nozongaku mena rokutja hijenene okuripeta; poo uina okukamuro zondjise omake uandje tjimaje hihamua." Participant 3

[I need assistance with putting on or taking off my clothes such as my trousers, socks, and shoes as I cannot bend; or even to comb my hair when my hands are paining ((pressing the sore points on hands)).]

"Ijoooh, ouzeu tjinene okunjinganjinga na uina mbimunouzeu tjimeso kujenda kokaruuo. Otjina otjizeu tjinene oondi tjiuhina kurihukuro omburukova, okuhaama nokurikutura. Participant 4

[Iyoooh, ((shaking head)) it is very hard to move around during a flare and quite devastating when you need to go to the restroom. The real problem starts there when you have to take off your trousers, sit down and clean yourself ((clicking tongue)).]

"Ha Matsogo ame ha a rurugile ((o bula a tswala matsogo)) ke tlhoka thuso, ka gonne go thata go itlhapisa le go ikapesa." Participant 10

[When my hands are swollen ((opening and closing hands)) it makes it hard to wash myself and dress myself. I have to be helped with all these things.]

Bathing/showering, grooming/personal hygiene, dressing, toilet hygiene are some of the six basic activities of daily life (Farlex Partner Medical Dictionary, 2012; Stamm, Pieber, Crevenna, & Dorner 2016).

Gout compromises functional independence for performing activities of daily life and consequently, the quality of life (Dewit, Stromberg, & Dallred, 2016).

Physical impairment occurs when the physical capacity to move, coordinate actions, or perform physical activities is significantly limited, impaired, or delayed (Massachusetts Department of Elementary and Secondary Education, 2000).

3.4.1.2.2 Sub-theme 2: Experiences of inability to execute instrumental activities of daily living

- Participants reported needing help from family members for household chores like cooking and washing, ambulation for getting to the doctor's consulting room.

These participants expressed their sense of loss in this regard:

"Hey, it's aggravating, not being able to drive your own car. So I can't really go anywhere nor do anything in that sense. I need someone to drive me to the doctor or visit some friends". Participant 6

"Whenever I need to go for follow-up my wife must put in leave to accompany me. There was a time when I was admitted to hospital] and I had to be washed and shaved by my relatives to make me look presentable". Participant 5

Instrumental activities of daily living (IADLs) let an individual live independently such as moving within the community visiting, shopping for groceries and necessities, going to the doctor on your own and taking prescribed medications (Mlinac & Feng, 2016).

- The inability to take care of the family in terms of doing washing, cooking and cleaning dishes, even the surroundings was aired by some of the participants and this made them feel useless and guilty that they are failing in their duty.

The following participants had these to say:

"It disables me to the extent that I just can't even walk to the kraal or clean my yard. I have to hire someone [shaking head], things I used to do myself." Participant 5

“My kleinkinders se klere word deur ‘n huishulp gedoen sedert hierdie problem begin het. As dit erger is, kook sy voor sy huis toe gaan. My kleinkinders hou van ouma se kos ((sy lag met een oog toe)).” Participant 7

[My grandchildren’s washing is done by a domestic worker ever since this problem started. When it is terrible, she does the cooking before she goes home. My grandchildren like grandma’s food [laughing with one eye closed.]

Cleaning and maintaining the house, preparing meals, shopping for groceries and necessities are some of the instrumental activities of daily living (Mlinac & Feng, 2016).

- Participants expressed how they felt helpless in situations when they seemed not to have privacy especially when nature called. They regarded these instances as overwhelming.

These negative experiences were expressed by the following participants:

“My whole life comes to a standstill when I have an attack. Og ((clap hands once)). I can't function at all like going to the toilet or moving around. I have to be assisted in all of these”. Participant 5

“I will stay in the bed for days while I wait for it to subside. It is even more frustrating when you want to go to the toilet. Someone must bring the urinal or bedpan ((pointing the bedpan)).” Participant 6

- As discussed elsewhere, pain comes whenever it decides, accompanied by its degree, and wherever it wants to attack. One common effect of gout in the knees is stiffening, in addition to the pain and inflammation. Such effects will probably make sufferers immobile.

This experience was stated by the following participants:

"Omuihamo tjiuri momunue ungara mbwae, ngaukare mozongoro, poo mozondo, poo parue, panga randje tjiua kutja urimouzeu ((okutaka otjiuru))." Participant 2

[Getting that pain in the toe I consider it relatively tolerable, compared to if you've got it in your knees or hips or somewhere, eish, then my friend, you have a problem ((nodding head)].

"Merikoho motjaua pendje nokurikohera mokatemba, kutja omukaendu uandje omukaendu uandje uso kukara popezu okundjiparurira ozokrana." Participant 3

[Taking a shower instead of climbing into a bath is the best option for me, although my wife must be nearby to turn the tap for me ((blushing)).]

3.4.1.3 Theme 3: Participants experienced loss of social relations

The impact of gout on the life of patients and their families can be substantial if gout flares cannot be controlled. The intense pain of a flare can be debilitating, leading gout patients to isolate themselves from those around them in order to limit possible physical contact, and also due to their reduced self-efficacy in personal care (Robinson & Horsburgh 2014).

3.4.1.3.1 Sub-theme 1: Experiences of isolation.

- Participants felt the gout condition and their appearance elicit pity from their friends. They also felt that their friends considered their condition as a bad situation, which expressed a negative evaluation and they therefore preferred to keep clear of them

The following statements attested to this:

"Dikgang le botsala jwame le ditsala tsame tsa kgale, ga di bolo goswa ka fa rele mmogo ba bua fela kaga bokoa jwame, jaaka o kare ba nkutlwela botlhoko ((o itswere phatla))." Participant 12

[My communication with my longtime friends has since died a natural death as their conversation goes around my conditions as if they pity me ((holding forehead in hands)).]

"Pain made me change in a lot of ways with my friends, family and the people that I am normally around with. It has an impact on the way your conduct yourself". Participant 6

The impact of gout goes beyond just joints; gout can have a substantial impact on the lives of individuals and their families. Rates of stress, depression and anxiety are increasing and this increase could include increasingly levels of social loneliness and isolation, as seen in individuals suffering from chronic conditions (Henriques, 2017).

- Participants regarded the unpredictability of gout and its effect on the plans as a matter of concern. Gout can ruin their plans and they were uncomfortable with the unpredictable aspect of gout flare. They stated that going out as a change of menu may end up in a disaster, or planning to go for an invitation could end with disappointment even for those who invited you.

These experiences entailed the following:

"Yoh! Eating out at restaurants is out, as the episode comes any time, meaning that the outing will have to be interrupted". Participant 14

[Yoh! Go ya go jela kwa di resturanteng ga go kgonagale ka ditlhabi di tla nako nngwe le nngwe hela, mo go rayang gore lo tlaa tlogela goja.]

"It affects my social life such as going to dinner, church, movies, and other functions [looking down at his feet]." Participant 5

"Daardie ding kom so onverwags, jy weet jy kan n plan maak, miskien vir jou voorberei vir n troue in twee weke se tyd, soos die dae nader kom, dink jy net Liewe Vader (.) ek hoop net ek kry nie daardie aanval nog die aand voor die troue." Participant 8

[It's the unpredictability of it, you know, you make a plan to, I don't know, maybe go to a wedding in two weeks' time and when it gets closer you think Dear Father**,** **(**.) I hope I don't get gout just the night before ((laughing))].

The pain associated with recurrent flares can also lead to reduced participation in social and recreational activities as patients seek to minimize the chance of precipitating a flare or being caught away from home when one occurs.

- A gout attacks can bring embarrassment in public arenas. One participant recalled an instance where he hit a small stone with his gouty foot. He said he cannot in words describe the painful experience he went through as he sat on the nearest stone he could find.

The following was expressed by one participant:

"Ek kon myself nie keer toe daardie aanval kom en ek is tussen mense nie. Weet jy daardie ding maak jou net 'n slegte mens tussen die mense. Jy kan maklik huil of selfs vir jouself natmaak. En dis wat gebeur het." Participant 10

[I don't want to be around anybody during the attack, yoh! It has an impact on the way you conduct yourself among people. You can easily cry or even wet yourself.]

3.4.1.3.2 Sub-theme 2: Experiences of lifestyle changes

- Making lifestyle changes are hard because it requires us to reset patterns we may have followed since childhood, it requires some re-training. Making it something you enjoy will help you stick with this new lifestyle change.

The following statement is evidence to this:

"((Giggling shaking head)) Gout pain has changed my life in a lot of ways (.) I had to accept a lot of things that I did not want to. You must be careful and on guard in whatever you do, wherever you go and whatever you eat or drink, ((laughing)), and I think also whoever you have conversation with mm". Participant 5

Their lives changed in a lot of ways due to gout such as recreational activities adjustment and dietary modification. Gout affected not only their ability to continue their hobbies, but also their habit of going to church, movies and to dine out.

Recreational activities adjustment.

- It was demonstrated that gout with all its' requirements to keep it at bay was inducing some emotional reactions and frustration among the adults suffering from gout.

Adults suffering from gout expressed themselves as follows:

"I had an attack during a vacation, shu! I couldn't do things we normally do during such outings and everything for me was spoiled". Participant 6

"I can't go on excursions with my brothers like I used to do ... [sighs]. My hobbies are affected such as fishing, riding motorcycle. Playing music at discos ... hunting and just running at my village were all hobbies with my pals. Horse riding was the best of all, hey, hey". Participant 5

"Og! Ke tlogetse metshameko e le mentsi e kene ke e tshameka (.) ke kgwele ya dinao." Participant 11
[Og! I had to give up sports I played my whole life, (.) that is soccer.]

Adults suffering from gout stated the following:

"Selo ke gore, ka ga ke itse gore mogote o tlhaga leng, le gone ga ke ipatle mo gare ga batho nako ya mogote wa kaote, ke khutlile go tsenela diphutego tsa mo gae le kereke tota ((o leba dinao tsa gaagwe))". Participant 14

[I don't want to be around anybody during the attack therefore I do not go out to church or movies ((looking down at the feet)).]

"Eish! I miss going to church, movies, and other functions like school bazaars, family events". Participant 5

Sorrow is felt for all that has been lost. Spiritual distress may be experienced when the person is faced with these limitations of the illness or disability that has occurred (Dewit et al., 2016).

Dietary modification

Namibians are known to be keen meat-lovers, and in the local parlance the saying goes that a meal without a succulent piece of steak is incomplete (Gaomas, 2007).

- When adults suffering from gout were asked about their diet to lessen the severity of gout, they shared common frustration of being advised not to eat a variety of food that they dearly enjoyed such as red meat, and their favourite beverages such as clubman and other soft drinks.

Supporting this observation one participant said:

"Nna hela jaana' ke ratile nama e khibidu, ke be ke inwela Clubman yame. Jaanong ka ntlha ya one mogote o, ke tlamegile go ja nama ya koko hela, le one go khutlela Clubman. Ai (.) Dijo jaanong ga di utlwale sepe le gone di ditshetla hela ((o a tshega))". Participant 11

[I like my red meat with my Clubman [beer] and now I must eat chicken all the time and avoid taking my clubman. Ai (.) It is so tasteless and boring ((he laughs)).]

"This disease affects what I can eat and I can't have a few drinks without a flare, yoh! I shouldn't eat red meat, even though I love it, must stay away from fish, steaks and some other stuff like beer and those are the foods I enjoy most [laughs]". Participant 6

"Nama ya kapana ka ditomate tse di tswisitsweng ka peppere le letswai, ke tsone dijo tse di monate tsa letsatsi. Mme ke gore ha ke ile ka dija, bojalwa, dikoeldramka le juice ya lemoen go raya gore, le ha ebile ke seka ka leka go di utametsa ha molomung wame." Participant 14.

[Fried meat at the okapana with seasoned tomatoes and onions are the best meal for the day. Adding to that, I should not take alcohol and soft drinks like orange juice].

"I am told not to drink alcohol especially beer, my favorite". Participant 5

- The adults suffering from gout seemed to be frustrated and confused by the information they were given concerning what to eat and drink and what not to. They were even more startled and surprised when they saw the list of food to be avoided, food they have been eating their whole lives long.

Adults suffering from gout verbalized their experiences as follows:

"Gansti ke tshwanetse ke ele tlhoko gore ke ja eng (.). Ga ke kake ka ja sengwe le sengwe ha ke ile gongwe, gonne ke tshaba bogale jwa mogote wa kaote o tsoga ((o a tswinya))." Participant 14

[I always have to watch what I eat (.) I won't eat anything when I go out somewhere because I am afraid the food might flare up my gout ((clicking tongue)).]

"Pelaelo ya gore tota tota ke dilo tse dihe tse di gakatsang kaote kgotsa dino tse dihe le gone go a tena ka dinako tsotlhe. Fa o le mo dipitshong kgotsa medironyana, o tlamega go ja se o se itlhopelang jaaka okare o mongwe wa maemo ((O tsikinya tlhogo))." Participant 10

[The uncertainty about exactly which foods and alcohol to avoid, food items causing flaring-up of gout is not nice at all. When you are at functions and parties, you have to be choosy as if you are the gentleman of honour. ((Shaking head)).]

Chronic pain is more than just physical; when it requires changes in lifestyle, it is sure to cause stress. Lifestyle changes, requiring dietary modification and adjustment of recreational activities can be overwhelming, especially if one has a limited support system in place (Nevada Pain, 2016).

3.4.1.3.3 Sub-theme 3: Experiences of change of social role

Reflecting on their young good days and their current situation, the following adults suffering from gout recalled how they were in charge of their lives:

"I used to go for soccer and rugby, visit with my friends and relatives. Teasing each other over our childhood days was always fun [smile]. [Giggle] when any of us got into a fight and lost, he would come looking for his brother or cousins to settle the matter, to support one another." Participant 5

"Gedurende die tyd wat ek nog gesond, sterk en dapper was, as ek nee gesê het dan was dit 'nee' en klaar, maar nou, hier is ek vasgenael in n rolstoel. My kinders dink net hierdie is n gefrustreerde iemand. Baiemaal moet ek maar alles laat gaan." Participant 8

[During the time when I was healthy, strong and brave, my 'no' used to be 'no', but now that I am confined to a wheelchair I feel that my kids will just think that I am a frustrated somebody. So I just let go most of the time].

"It wasn't easy at the beginning of our marriage. I wanted to remain a young man still, our weekends were marked by braaivleis and alcohol, music and dancing, but gout cut that type of behaviour very short". Participant 5

When chronic illness causes the loss of function, usually roles may be changed. In this sub-theme, adults suffering from gout referred to the re-identification and value transformation relating to the people they had been, and who they currently are. Daily patterns are altered to accommodate treatment and therapy to cope with the problems of the disability (Dewit et al., 2016).

As an ex-combatant one adults suffering from gout reflected with a hint of anxiety on the days when they were in Katima Mulilo by stating the following:

"Omapanga omengi ngumbinauo nai tuahakaenena momakuturiro uorutu tjituari morupa rovita kombundo ngutukiro. Otukara nenjando pamue. Ngamba tuatiza otutu tuetu naua amaturirongere kotjirua ngamua atjihe tjimatjija. Tuari omapenda mokati kombura, orutjeno, omitenya nauina mozongaro ozombi zozokamba mutuari." Participant 2

[Many of my current friendships have been formed when we were in military training before independence. We enjoyed activities at our place for fun. Still, we kept our bodies in fine shape for any battles that might come up. We had to brave thunder, lightning, extreme temperatures and terrible condition of the camps].

Most people are not sufficiently prepared, either psychologically or practically, for being cared for when they fall into a disabled condition. The person may no longer be able to be the prime income provider nor hold the position in the workforce or community that formerly was held (Dewit et al., 2016).

- It is of human nature to try and avoid talking about experiences that are emotional. Another adults suffering from gout cut his confession short as if it was digging up unpleasant memories as he stated the following:

"The last few weeks for me have been a very different emotional experience, something I never thought I would feel myself ... but let's not talk about it". Participant 6

An overview of the themes and sub-themes obtained from the perception of participants' experiences of caring for their relatives suffering from gout during the data gathering process are presented in Table 3.2 below.

Table 3.2: An overview of the key themes and sub-themes identified from the caregivers

Key themes	**Sub-themes**
Theme 4 Participants experienced negative feelings physically and emotionally	**Negative feelings expressed as:** Sub-theme 1: Physical fatigue Sub-theme 2: Emotional exhaustion Sub-theme3: Increased instances of chronic insomnia
Theme 5 Participants experienced social disconnectedness	**Social disconnectedness expressed as:** Sub-theme 1: Limitation of social network Sub-theme 2: Lack of social support to care for their family members with gout.

3.4.1.4 Theme 4: Participants experienced negative feelings physically and emotionally

Any chronic disease can cause many emotions, including grief and a sense of isolation for both the cared for and the caregiver (Hulme et al., 2018). Fatigue is a common symptom of a variety of chronic illnesses and conditions. In this study, fatigue can be viewed as a patient or caregiver perceived lack of physical or mental energy that may interfere with the performance of usual and desired daily activities" (Cameron, Peterson, Boudreau, Downs, Lovera, Kim, McMillan, Turner, Haselkorn, & Bourdette, (2014). p. 1).

3.4.1.4.1 Sub-theme 1: Experiences of physical fatigue

Caring activities during the day and especially during the night were reported by most caregivers as often being "on call" and they felt their lives were halted and are dominated by feelings of exhaustion. The findings of the focus group discussion go along with the experiences of adults suffering from gout of being depended on others.

“Ga ke robale bosigo, o nna a mpitsa go mo thusa, gantsi fa a batla go pitokologa (.), le gone go ya kwa ntlwaneng ya boithomelo”. FGD 2

[I do not sleep enough, as he calls me during the night to help him turn (.), or to assist him to go to the toilet].

“Boroko jwa bosigo le jwa motshegare go tshwana hela, ga ke robale kwa ntle ga gore a ntshwenye. O tla a nna a mpitsaka, ((o goga sefatlhogo a tsikinya tlhogo)) ele dira jaana, o dire sele.” FGD 4

[It is the same during the day, even if I want to take a nap I will be called ((with a frown and shaking head)) to do this or that. I do not sleep uninterrupted.]

“Ka dinako tse dintsi go na le gore o batla go tswa mo bolaong, a batla go dula kgotsa go robala mo setulong, tsotlhe tse ke nna ke di modirelang ke le nosi, [o kaya monwana] mmele wame le one jaanong osetse o heleletse.” FGD 5

[Many a time he wants to get out of bed and sleep/sit on a chair, I am the one to assist him in everything [showing with a finger] and physically I am exhausted.]

Ditioro tsa mo lwapeng le go mo tlhokomela go a nkimela, ke ikutlwa ke tlhoka mothusi. Ke nna ke lapile dinako tsotlhe, ga kena thata epe mo go nna. E tlare hela a batla melemo, ya be ele ka nako eo ke lemogang ha ke heleletse le mogopolo tota.” FGD 5

[Cleaning both him and the house is done by me and I feel someone could help. I am constantly tired and feel a lack of energy and feel tired most days. When he reminds me of the medication, only then will I realize that my mind is tired].

Evidence suggests that the quality of care provided to patients with gout may impact their health-related quality of life (HRQoL) for which caregivers have to carry the brunt of the burden (Singh, 2009). Patients with gout may need to be helped with their personal safety, for instance compliance with medication, and even for basic activities of daily life and social involvement, resulting in highly demanding tasks for caregivers.

In a study conducted by Haynes-Lawrence, & West, (2018) caregivers described their physical fatigue as unyielding and overwhelming feelings of tired and heaviness; a heavy feeling, pressing down on the body. The heaviness of the body impacts the ability to complete tasks.

3.4.1.4.2 Sub-theme 2: Experiences of emotional exhaustion

- The feeling of being undervalued was expressed by one caregiver when she stated:

"Molwetsi yo, ga ana perekisano mmogo, ga a na tebogo e pe mogo ene, ga gagwe ke go nne hela go ntlhokisa boroko malatsi otlhe, a ngongorega hela di nako tsotlhe. Ga a na tlhompo niks mo go ene ((ka dikeled))." FGD 5

[Refusing to cooperate and being over-demanding can make me so upset that at times I keep awake most of the night feeling unappreciated ((shedding tears)).]

"Bosigo ha a batla go dirisa ntlwana ya boithomelo, ke tlamega go ema ke mo thusa. Ha ke sa eme ka bonako, o a nkgoelela." FGD2

[Him using the bathroom at night forces me to get up to assist him. If I am fast asleep and do not respond on time, he will scream on me.]

"Go utlwisa botlhoko ha o tshwere tiro e e kanakana, go sena ope mo go balosika yo o lemogang o rwele morwalo oo go imelang. Go ntshwenya tota go mmona ale mo ditlhabing tse di mo ledisang e le ruri". FGD 3

[It grieves me that no one of the family seems to realize the burden I am having. It is quite disturbing for me to see him in pain or crying].

Caregivers are often required to consider the emotions of their clients, making their work susceptible for burnout. Extending recent developments in connection with dehumanization, Vaes and Muratore (2012) found out that humanizing a patient's suffering positively predicted symptoms of burnout, especially for those participants that have higher levels of direct contact with suffering patients.

Caregivers have been found to have increased depression scores, an increased burden load, and poor social lives and, in general, diminished quality of life and caregiving for an individual while trying to work can be exhausting (Elizz, 2016).

In a study conducted by Haynes-Lawrence and West (2018) most participants mentioned the inability to feel rested, even upon waking, that sleeping all night and into the day. Instead they felt irritable all day.

3.4.1.4.3 Sub-theme 3: Experiences of increased instances of chronic insomnia

- It was obvious that most caregivers were having problems with sleep patterns in relation to the sleep pattern of the person they are caring for. If the person cannot fall asleep because of pain, they will be restless which will also keep the caregiver awake.

The following comments are evidence to this:

"Bosigo ha ditlhabi di tlhagela, o tlabe e le gore o tla duma, a pitokologa mo bolaong. Nako ewa, ke ikutlwa dithlabi tseoa. O kare gotlhe mo ke go dirang, ga go thuse. Le gotlhe mo ke go dirang, go oketsa ditlhabi. Gotshwa foo ga ke kitla ke kgona go robal " FGD 5

[At night when the pain becomes so severe, he keeps on groaning and tossing about in bed. That time, I feel as if I am experiencing the pain myself. I feel like nothing you do is really helping. And everything you do hurts. I won't be able to sleep thereafter].

"E tlare hela a kua ele ditlhabi, ijooo, ke gore ke tshoga jaana gore, pelo yame [o itshwara sehuba] e tla roroma jaana gore, ijoo wee, ke tla be ke tlhoka boroko, go sena jaaka ke tla thulamela le ha ele." FGD 1

[When he screams I become so scared that my heart [touching her chest] starts to beat very fast, making me unable to go to sleep].

"Fa bosigo a itshenyetsa, ke tshwanetse hela ke mo phepafatse ke phepafatse bolao, gonne o ya go nna a ngongorega a sa ikutlwe sentle. Mo nakong eo owaii ((a tshikinya tlhogo)) boroko bo iketse, weg, bo ile." FGD 3

[If he messes up during the night there is no option but to clean him and change the bedlinen because he will keep on complaining of the discomfort, by that time ((shaking head)) sleep is gone.]

Sleep problems are associated with mood and function disturbances in caregivers of persons suffering from chronic disease. It is known that sleep disturbances can originate from a combination of a non-conducive sleep environment, cognitive hyper-arousal and rumination. (Cresto, 2014).

Caregivers' sleep, like those of older adults, has considerable night-by- night variability, and that caregiver reports of their own or their care recipients' sleep quality are not always congruent with what would be expected based upon objective measures of their nighttime sleep or activity. (Cresto, 2014; McCurry et al., 2009).

Some caregivers expressed their personal problems with sleep. They sleep very shallow and have problems falling asleep after being woken up in such a frightening fashion. They are also often disturbed by the restlessness of the person they are caring for.

The following statements are evidence to this:

"Go a nkimela gore ke tle ke robale motshegare, thata gone ha o ile wa tshwenyediwa boroko jwa bosigo. Le gone jalo, go thata go thulamela thata, bogolo thata jang ha mmele o lapile." FGD 3

[It is difficult to sleep during the day after an interrupted night sleep. On top of that I sleep very shallow, the problem becomes worse when I feel tired.].

"Gantsi ke motlhoki wa boroko, ha ke tla heta ka kubuga gangwe hela, ((o tsikinya tlhogo)) ga kena go thulamela gape." FGD 4

[Generally, I am a poor sleeper and I have problems going back to sleep once I wake up ((shaking head)).]

The study conducted by Cameron et al. (2014) shows that, for many individuals such as caregivers of adults suffering from gout, fatigue is associated with poor sleep quality.

- Even when one caregiver has an option to take a sleeping medication to sleep better, she was afraid to fall into deep sleep in case the adults suffering from gout might just scream and she is woken up suddenly.

The caregiver stated the following:

"Ke na le bobohi jwa go nwa dipilisi tse di robatsang, ka gore hela jaaka a tla kua bosigo, ijo mma wee e tlabo e le gore ke a kgogoga, ke tlhakatlhakane tlhogo, ((o gogile sefatlhogo, o leba dintlha tsoo pedi)) ke sa itse gore hela gatwe ke ha kae, ke tshware ha kae, ke simolole ha kae." FGD 2

[I am afraid to take sleeping medication because when he screams at night I become so confused [with a frown and looking left and right] and disorientated, not knowing where to start].

Little attention has been paid to treatments to improve sleep in caregivers (Cresto, 2014).

3.4.1.5 Theme 5: Participants experienced social disconnectedness

In the previous discussion, the caregivers had summed up what they are going through in caring for their relatives and loved ones. These experiences were in addition to their experience of being socially disconnected and lacking a social network.

3.4.1.5.1 Sub-theme 1: Experiences of limitation of social network

- Caregivers felt they were living alone despite staying with the people they were caring for. Living alone, having few social network ties, and having infrequent social contact are all markers of social isolation.

"Ga se ka dinako tsotlhe go na le baeng hano, ga go a tlwaelesega, ke gone jaaka gantsi ke le esi ke sena le ope yo ke jang dikgang le ene. Heela, ka ke nna ke theogetse hela nako yotlhe, ga ke na le ha ele tshono ya go nna le ditsala he itisa kgotsa hela go dula he ja dikgang" FGD 3

[It is not common to have visitors coming here, and you find yourself all by yourself with no conversation at all. Being busy all the time, I do not have the opportunity to visit with my friends or to communicate with them.]

"Owaiii, nako ya menate ga e yo, a ke manyalo, a ke meletlo ya eng kgotsa eng, le ha ke biditswe, ga ke kgone." FGD 1

[I do not have time for leisure, even to go to parties or weddings when I am invited.]

- Caregivers commented how they felt trapped in the house as they can't go to community meetings, church and other events. In addition, no one comes to give feedback on all of these.

The following statements were uttered:

"Go dithulagano mo gae le kwa kerekeng, ga ke itse ka tsone, gonne ga ke kgone go tsenela dilo tsa mefuta eo." FGD 4
[Things are done in my community and at church and I am not aware of them because I do not go to such functions.]
"Ha go na le dikopano le merero mo motsing, ga nkake wa bona ope hela a tla go rerisana le rona ka tsa kopano." FGD 3
[There is no feedback from whatever is discussed in any gathering or events that takes place in our village.]

According to Holt-Lunstad et al., (2015) in previous research, a lack of social connections and social relationships has also been linked to caregiving. In support of the above, Zebhauser et al. (2015) say that presence of depression and a lack of functioning social network are the most important leading causes of loneliness. Adding to this notion, some data have shown that those who were both high in loneliness and isolation had the poorest immune response (Grant et al., 2009; Hawkley & Cacioppo 2010).

Engaging in social interaction for fun and recreation appears to be most important in diminishing the burden of caregiving. Further, interventions that ensure that caregivers regularly experience pleasant activity with friends and family members would seem to go a long way toward managing the burden of caregiving (Pristavec, 2018).

3.4.1.5.2 Sub-theme 2: Experiences of lack of social support to care for their family members with gout.

- The majority of caregivers were family members, and upon reflecting on their experiences of caring responsibilities and their support network, they observed that their support network was wanting.

The following observations were made to this effect:

"Ga ke gakologelwe gore ke leng wa losika a tlile go re okomela go bona gore re tshoga jang. Ga ke sa tlhole ke ba bolelela mathata a me le go tsaya maikaelelo." FGD 2

[I can't remember when last any of our family members popped in to see how we were doing. I have since given up on talking about my problems with my family to help me make decisions.]

"Ka baitse gore ha kaote e motsenenetse o ntse jang, le gone gore maikutlo ame a ntse jang, ba losika le ba agalani ba lapetse go goa ga gaagwe, jaanong ba itlhokomologa." FGD 4

[Knowing how difficult he can get, especially when he experiences gout flares, and my emotions are done, my family and neighbours seem to be tired of his screaming at me, and they just ignore.]

In chronic caregiving, caregivers can be overwhelmed with multitask activities, including activities of care, personal and family matters. There is a broad amount of literature associated with the issue of lack of considering the burden of caregivers (Pristavec, 2018)..

- Outside relationships were also commented on as having gone sour as caregivers were talking about their encumbering task, and in some instances the patients were not co-operative with assistance from outside and would be abusive with their language.

The following statements are evidence to this:

"Go na le mokaulengwe, yo ke mo ikantseng thata, gantsi ke abelana nae maikutlo ame, a ke selelo kgotsa boitumelo. Jaanong ka ke nna ke bua ka ga ditiro tsame, ke dumela ha kemo tena." FGD 3

[I have a person who has been a real source of comfort to me with whom I could share my joys and sorrows. But because of me always talking about my tasks, I think the topic has become boring.]

"Tsala ya gagwe yo ba tseneng sekole mmogo, ke ene thata one a ithaopang go baakanya sengwe le sengwe se se robegang mo gae, kgotsa ha a nna a itshenya; le ene jaanong ga a tlhole a thusa sebakeng sa go gakala ga ga agwe" FGD 1

[His school friend was always around when I was in need of any home chores like fixing any broken article, or such times when he is continuously incontinent; he too is now reluctant to help because of his outbursts.]

"*Kene ke ikaega thata mo ditsaleng tsa gagwe tsa borre, ha o kare ke a gatelesega kgotsa ke a imelwa. Ga esa tlhole ele jalo. Ba tsamaile". FGD 3*

[I could count on his male friends when things went wrong such times when things were tough for me. It is no longer the case. They are gone.]

Social support is defined as a group of individuals who can help and support any person. Informal social support is defined as unpaid help or support from any individual. Research has been shown that lack of social support will lead to detrimental effects on one's health, particularly when stressed and burdened, leading to a negative effect on the immune system and thus to infection. Caregivers may also be easily frustrated which gives rise to negative acts in caregiving, such as abuse. As a result they will suffer from physical health problems such as chronic backache, musculoskeletal pain, cardiovascular problems and poor sleep, as well as reduced social activities and poor mental health. Previous studies have shown that these symptoms will have an impact on their quality of life (NurFatihah et al., 2013).

The daily routine of a typical caregiver reported in the literature:

Calvin's day begins before 5 A.M. He knows another exhausting day lies ahead. He allows himself only enough time to have a cup of coffee and read the paper before lying back down by his wife's side until 6 A.M. when the daily routine begins again; toileting, showering, dressing, wheelchair transfers, laundry, meal preparation, housekeeping, correspondence, paperwork, yard work, personal care. Soon it's time for a doctor's appointment; more wheelchair transfers, a trip to the pharmacy, grocery shopping, and then, finally, a return home to continue the care routine.

No time to rest during the day. Bedtime planning takes an hour so he begins by 9 p.m... Calvin is physically and emotionally exhausted by 10 p.m... and falls asleep quickly. But he is awakened and out of bed at least three times during the night, tending to his wife's needs, taking her to the toilet, or changing wet sheets. He attempts to return to bed and finds he cannot fall asleep. His mind is active, he feels anxious and has relentless thoughts that swirl in his mind. Daybreak seems to come too quickly and the schedule begins once again. Caregiving consumes 24 hours of the day, and sleep deprivation and fatigue are the common denominators. (Adopted from Dwyer, 2017 "Fighting Caregiver Fatigue")

3.5 Summary

This chapter described the findings of the study interviews based on Objectives 1 and 2 in relation to the experiences of adults suffering from gout and the experiences of caregivers in the provision of care. The findings from adults suffering from gout indicated that pain caused physical and emotional exhaustion, while physical fatigue in caregiving and emotional exhaustion were common denominators. There was a shared experience of sleep deprivation and lost social network and social disconnectedness which lead to isolation and sadness.

The central story line of the experiences of all these participants can be described as the absence of skills in managing the ill-health challenges that cause physical and psychological discomposure, and in addressing social disconnectedness. As the research clearly indicated the absence of skills in managing these challenges, motivation and social skills as elements of emotional intelligence are crucial to manage the negative experiences that accompany suffering from gout and caregiving.

The researcher was able to capture the storyline which was also supported during the literature control to emphasize and reinforce the study findings. This phase of the research helped the researcher to come to an understanding of the phenomenon as an insider.

Using Tesch's method of qualitative data analysis, it was possible to come up with themes as discussed below:

- Adults suffering from gout experienced holistic (physical and psychological) discomfort.
- Adults suffering from gout experienced increased levels of dependency on others
- Adults suffering from gout experienced loss of social network.
- Caregivers experienced different manifestations of negative feelings physically and emotionally.
- Caregivers experienced social disconnectedness.

The next chapter discusses the conceptual framework of this study.

CHAPTER 4: CONCEPTUALIZATION AND FRAMEWORK

4.1 Introduction

As indicated in the previous chapter, this study was intended to explore and describe the lived experiences of adults suffering from gout and the lived experiences of their caregivers' in caring for them (phase 1). A qualitative, phenomenological, descriptive design was therefore used to conduct this study. From the results obtained with regard to the lived experiences of adults suffering from gout and the lived experiences of their caregivers under study five (5) key themes and fourteen (14) sub-themes were identified which provided the fundamental structure of the phenomenon under probe. There was a universal expression of discomfort both physically and emotionally, social disconnectedness and loss of social relations for the adults suffering from gout and their caregivers, whilst excruciating pain, increased levels of dependency on others were experienced by adults suffering from gout.

A representation of the elements of a practice theory as described by Dickoff et al. (1968) was reflected in Chapter 2, Table 2.6 within which main concepts were classified and organized systematically following Tesch's steps of data analysis and its application to the study.

Phase 2: Development of a conceptual framework

Conceptualization of the findings derived from situational analysis.

Phase two dealt with development of a conceptual framework which served as a tool or basis for the development and implementation of a self-management programme to empower adults suffering from gout in the Omaheke region, Namibia and their caregivers to better manage their ill health.

It is much easier to talk about concepts by giving them names. The function of a name is to enable the mind to point out, denote or attend to a concept (Dickoff et al., 1968). If we do not have names for concepts, we cannot think about them, talk about them or compare them with other concepts (Brea, Creek, Meyer, Stadler-Grillmaier, & Faias, 2012). According to De Vos et al. (2011) and Dickoff et al. (1968) a conceptual framework may be perceived as a guide for the development and the implementation of programme activities. Subsequently, this conceptual framework served as a tool or basis for the development and implementation of a self-management programme to empower adults suffering from gout in the Omaheke region, Namibia and their caregivers to better manage their ill health.

The discussion in this chapter was based on the conceptual framework of Dickoff et al. (1968) using the reasoning map that is based on their survey list outline. The reasoning map is discussed below.

4.2 Classification of Central Concepts and Related Concepts

The researcher used a survey list from Dickoff et al. (1968) as a reasoning map in the development of the conceptual framework. Dickoff et al. state that a conceptual framework has the ultimate purpose of creating situations in order to attain the desired, preferred end results. These theorists contend that the survey list should respond to the six crucial questions about the activities to be performed. The survey lists in the current educational programme are *agent* (referring to the facilitators); *recipient* (adults suffering from gout and their caregivers); *context* (the relationships between the environment, personal factors and events that influence the meaning of activity for the performer); *dynamics* (health challenges of suffering from gout and of caregiving); *procedures* (development of a self-management programme); and *terminus* (acquisition of techniques to deal with health challenges)

Based on the above statement, the survey list was adopted as a reasoning map in the construction of developing a self-care programme. The use of reasoning maps is a powerful and useful approach for modelling knowledge and qualitative reasoning. In this study the conceptual framework was developed in relation to the themes that had emerged from the analysis of the data about the experiences of adults suffering from gout and the experiences of their caregivers (Dickoff et al., 1968).

They further identified three essential ingredients of a situation that produce a conceptual framework; namely the *goal* content, (the aim of the activity), *prescription* of the activity for goal realization, and a *survey list* that accompanies the presentation of the prescription for the activity in terms of the goal realization. The self-care programme includes the activities suggested in the survey list, namely, agent, recipient, context, dynamics, procedures, and terminus. They further constructed the reasoning map concept which referred to a structure of concepts that represented the interaction between the agent and the recipients, contextualized within a specific situation and process.

The goal content (the aim of the conceptual framework) was the aspiration to bring a situation into existence, i.e., to develop, implement and evaluate a self-care programme in order to assist adults suffering from gout and their caregivers in managing their ill health challenges. The prescriptions of the activities for goal realization are the guidelines for carrying out these actions. In accordance with George (2014) and Dickoff et al. (1968) these activities must be appropriate and, therefore, suited to leading to the realization of the goal content.

The conceptual framework of this study was based on the practice-orientated theory of Dickoff et al. (1968) which explains concepts and analyzes the prescribed activities that are aimed at realizing the programme goals, namely:

- Who or what performs the activities (agent)?
- Who or what is the recipient of the activity?
- In what context is the activity performed?
- What is the guiding procedure technique or protocol of the activity?
- What are energy sources for the activity?
- What is the end product of the activity?

4.3 The Researcher's Reasoning Map

The hierarchical representation of the reasoning map consisted of the following components: agent (the researcher/facilitators), recipients (adults suffering from gout and their caregivers), context (home setting), dynamics (health challenges), procedures (techniques to address health challenges), and terminus (empowered recipients). (See the reasoning map Figure 4.1). Each component consisted of elements that were part of the study findings, which assisted with developing a self-management programme for adults suffering from gout and their caregivers to empower them with knowledge, skills and confidence to take care of themselves. The reasoning map in Figure 4.1 below displays the components which consist of elements of the study findings.

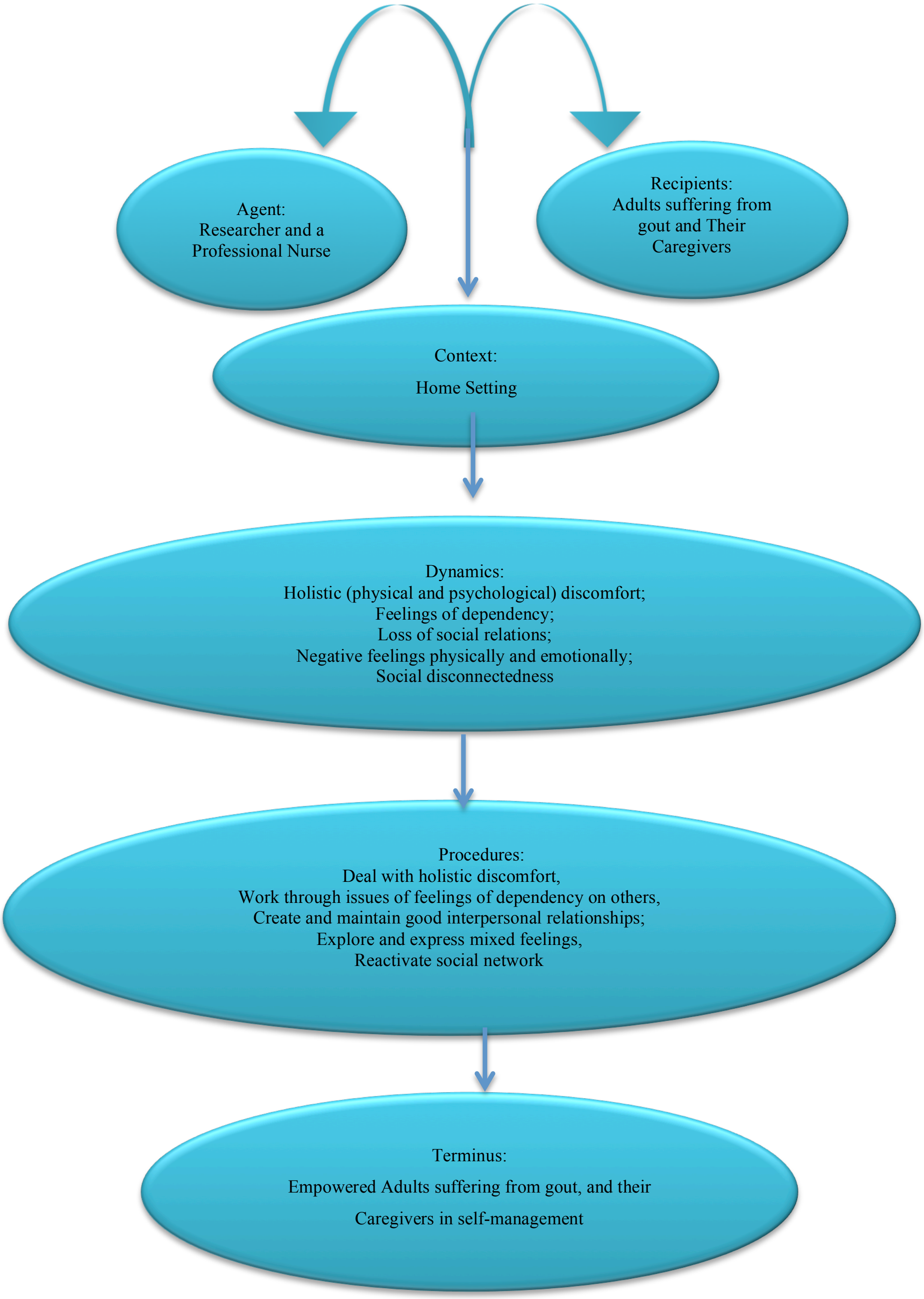


Figure 4.1: Reasoning map: Source: Dickof et al. (1968, p. 438)

4.3.1 Agent

The agent in this study refers to the researcher who facilitated the development and implementation of the self-management programme. The agent, as a nurse educator at a tertiary institution, has a broad experience in the field of research and in providing home-based health care through home visits with nursing students in the community. Figure 4.2 indicates the essential characteristics and abilities of an agent as explained in the literature.

Figure 4.2: The Agent: The Researcher (Facilitator)

The agent as a facilitator should have certain characteristics: the agent should display good interpersonal relationship, compassion, understanding and support towards the recipients. Support for self-management refers to the role that a facilitator plays in assessing and building client knowledge, skills and confidence to effectively manage their own health-care concerns and treatments. It is also important for the agent to be knowledgeable—an expert offering valuable advice and suggestions and valuing others' opinions and knowledge. Another characteristic of the agent is the supporting skills of learning, thinking and the ability to enact the knowledge thereby facilitating empowerment and support.

4.3.1.1 Characteristics of an agent

Couros (2018) believes that an agent is a catalyst for change and certainly embodies characteristics such as knowledge and skills that will trigger empowerment in the recipients. The agent must have clear vision, be patient and persistent, ask tough questions, be knowledgeable and lead by example and build strong relationships. In addition the agent should have inviting and attractive attitude by displaying supportive skills.

Clear vision.

The agent (facilitator) should not exert any authority over recipients, but should have a clear vision and understanding and to communicate that clearly with them. To have a clear vision is essential to identify their strengths and weaknesses, and share what they already know to other members of the group, and thereby helping them see that there are many ways to work toward a common purpose of empowerment. George (2014) states that an agent requires the skills and confidence to render care and counselling with compassion and understanding of those in need of care in order to realize the desired situation. In this instance, an agent should have a clear understanding of the health challenges that come about from suffering from gout and from providing relevant care.

Patience and persistence.

Persistence comes in that the facilitator realized that not everyone moves at the same pace. Every step forward is a step closer to a goal; agents just help to make sure that people are moving ahead. Dickoff et al., (1968) refer to an agent as a person who executes activities, a propelling force that moves an activity towards a goal, and is either a person or thing that produces an effect and takes an active part. Based on Ekman's (2010) assumptions, for this study the facilitator is an agent guiding adults suffering from gout and their caregivers on a "learning journey" in discovering their own lived experiences.

Asks tough questions.

The facilitator keeps asking questions to help people think. One of the roles of an agent is helping recipients come to their own conclusions based on their experience and feeling an emotional connection to the programme. Only then will recipients have ownership of what they are doing. According to Towell (2011) a facilitator/role model makes use of guidance, support and the mobilization of resources for formal/informal instruction to teach: problem solving, abstract thinking skills, reasoning skills and positive self-instruction over primitive reactions and behaviour. Towell (2011) argues that the responsibility for and control of learning are shared between the agent and the recipient, and Webb (as cited by Amakali, 2013) supports this by maintaining that the agent is to acknowledge the adults suffering from gout and their caretakers as individuals who have strength, unlimited capacity and the aspiration to grow and change and, in collaboration with the agent, they will be enabled to attain success within their own context.

Knowledgeable, and leading by example.

If agents want to create change, they have to be able not only to articulate what that looks like, but to show it to others. The role of a facilitator requires knowledge not only on the subject matter of the educational programme but should include a wide interest and awareness of the recipients (adults suffering from gout and their caregivers), as well as the community and/or society at large. In response to demands/questions for clarification by adults suffering from gout and their caregivers about what was discussed, the facilitator demonstrated mastery of knowledge and skills (Glanz et al., 2015) and was able to offer proper information and solicit ideas that enlightened the group. Proper knowledge makes the smooth interaction and discussion between the facilitator and the group possible.

Strong relationships built on trust and respect: ultimately, an agent needs to have solid relationships with the people they serve. Trust, approachability and reliability are what will push people to want to grow. All types of successful relationships are built on trust. This makes a strong and basic foundation for any relationship, whether personal or social. A facilitator has to win the trust of adults suffering from gout and their caregivers in order to easily deal with them. Trust is that feeling of reliance and belief in each other when fairness is manifested between the facilitator and recipients. Cooperation and respect from the recipients is one positive outcome of a good relationship. They will show their respect as their facilitator (Exforsys, Inc., 2010).

4.3.2 Recipient: Adults suffering from gout and their caregivers

As described by Dickoff et al. (1968), the second aspect of the activity in practice-oriented theory is the recipient. The recipient refers to any person, who for their benefit and interaction with the agent receives action from the agent in order to realize a goal or a desired situation. They are defined as the people who are on the receiving end of an activity. For this study, the recipients are the adults suffering from gout and their caregivers at home for whom the programme will empower with knowledge on interpersonal relationship and the self-care abilities; and to be open to motivation and receptive to the self-management programme. They should possess certain characteristics as displayed in Figure 4.1 below.

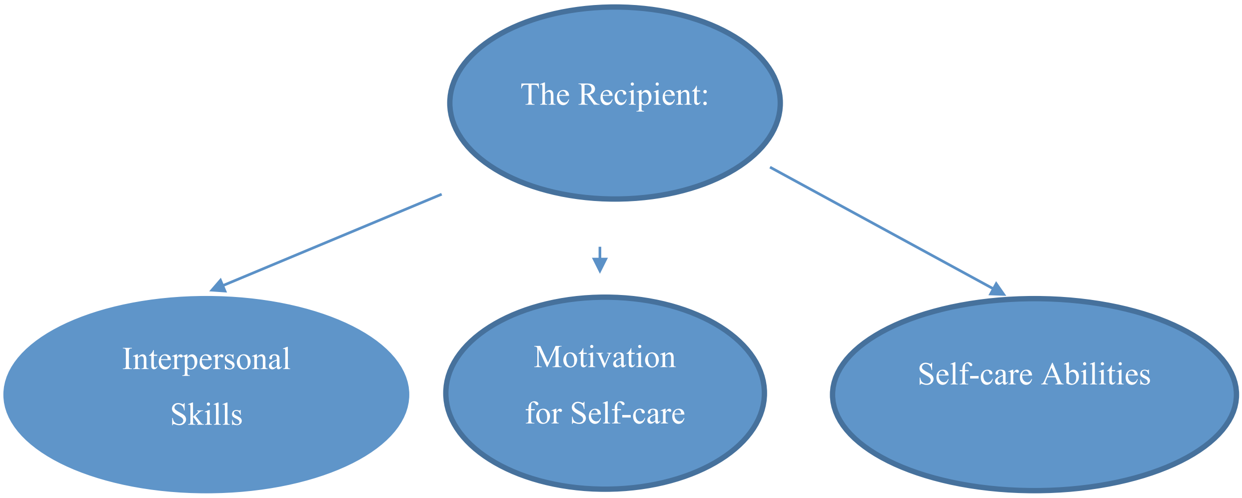


Figure 4.3: The Recipient: (Adults suffering from Gout and their Caregivers).

It transpired during the data analysis (Chapter 3) that the two groups of the study (adults suffering from gout and their caregivers) lacked the management techniques and strategies to deal with the physical and psychological challenges that came with suffering from gout and with rendering of care, respectively. The searcher also discerned other challenges of social disconnectedness which originated from the same experiences. For the sake of easy discussion and explanation, the two groups (the adults suffering from gout and their caregivers) were to be dealt with separately where appropriate.

4.3.2.1 Characteristics of a recipient

Interpersonal Skills

A good and trusting relationship between the caregiver and the client is one of the most important factors on how well they will handle a change in life status. Trust is the most important part of building this relationship. Forming a good connection from the first encounter can help in building a long-lasting trust that will become a wonderful experience for both parties. Often the client and the caregiver are surprised at the connection that grows between them, to the point where they become accustomed to seeing each other, talking and sharing about their lives and learning from one another (Strawther, 2015). Both the caregiver and the client need to be open to the experience and the many factors that will affect the outcome. Consequently both the adults suffering from gout and their caregivers need to work on their relationships in order to realize the goal of the helping process.

The client will begin to trust the caregiver with important factors of their day-to-day life and appreciate their presence and assistance. While the caregiver will find that it is not easy to deal with another person's health difficulties, they will learn to appreciate the grace that is life and humanity, which can be a rewarding and unforgettable experience.

The caregiver

For the caregiver to be successful as a caregiver they must have emotional strength to handle assisting someone in a position they did not choose for themselves. They must understand that the client may take their emotions out on them when in reality they are upset at the situation. Also there are many medical conditions that make it impossible for a patient to control their responses, and caregivers deal with these daily (Strawther, 2015).

It takes courage and confidence to work with certain individuals, to accept their circumstances and have the compassion to assist them while they are in a vulnerable position. You must always look out for the best interests of your client, including using outside resources if things are out of the ordinary or unsafe. However, always remember your goal is to assist a person in keeping or restoring their independence, not to take it from them. Until a caregiver earns the trust and respect of the client, the caregiver is simply a guest in their home.

The client

For the client, it is good to remember that it takes courage to admit that they need assistance with tasks they may have done with ease a year or even a week ago. Always communicate the needs as much as possible with the caregivers. It can be difficult when a person is feeling sick or weak to ask for help but the caregiver must try not to let a fear be a hindrance from providing the assistance needed in the home and life of the person needing help (Strawther, 2015). They must try to remember that, although the caregiver might be paid, they are in the home to work *with* the patient. The partnership and the caregiver should be respected.

Motivation

The concept of motivation can only be fully understood in terms of its similarities to, and difference from, the related concepts of volition and engagement. Motivation, volition and engagement form a cluster. They are all terms linked to the energy source for action. A person feels a need to act (motivation), chooses how to act (volition) and, because the act is voluntary, the person experiences the sense of involvement in what is being done (engagement) (Brea et al., 2012).

Motivation is defined as the process that initiates, guides, and maintains goal-oriented behaviors. Motivation involves the biological, emotional, social, and cognitive forces that activate behavior. "The term motivation refers to factors that activate, direct, and sustain goal-directed behavior... Motives are the needs or wants that drive behavior and explain what we do. Motives are only inferred to as existing based on the behavior we observe.” (Nevid, 2013).

There are three major components to motivation:

Activation involves the decision to initiate behaviour. *Persistence* is the continued effort toward a goal even though obstacles may exist and it requires a significant investment of time, energy, and resources. *Intensity* is seen in the concentration and vigour that goes into pursuing a goal (Cherry, 2018).

With regard to the recipients, motivation is the ingredient that defines the difference between desire and determination in the process of setting and attaining goals. The recipients are expected to be determined in motivating themselves to take appropriate action for self-care, to be committed, to follow-through, and to work intensely toward the achievement of self-care abilities. George (2014) points out that willingness, as the power of the mind to make a decision and to act in accordance with this decision, is a driving force to engage in that action.

The caregivers are expected to have a sense of responsibility in the caring process in terms of being available and accountable towards their clients by meeting the demands of care (Stajduhar et al., 2008). They should have an understanding of the nature and the pain of gout and its physical and emotional effects on their clients.

Motivation for Self-care

Successful ill-health management is like a team sport, and the recipient is the main player if the team is to win the match. The recipient needs to take the decision to initiate behaviours of self-care with the assistance of a supporter with motivational skills to serve as the primary motivator of important daily routines such as diet, exercise, weight management, medication adherence and compliance; fatigue management, venting of emotions and social connectedness. Poor adherence to these important daily routines affects virtually every condition. It is a problem largely rooted in a combination of human irrationality and insufficient motivation (Firlik, 2011).

The healthcare recipient doesn't want to feel old, or to be reminded that they are a patient with a condition; they don't want to put up with annoying symptoms, even for a short while, nor to be inconvenienced by health maintenance techniques. Firlik (2011) observes that it is exceedingly difficult for many people to maintain the motivation to be engaged in important daily routines today, tomorrow and the next day, when the benefit may be years away. Humans crave more immediate gratification. Talking about a healthy lifestyle is largely a value problem. Despite the long-term benefits, patients often don't perceive sufficient short-term value in their health maintenance techniques or a healthy lifestyle.

Motivational interviewing (MI) is believed to improve unhealthy patient behaviours and to increase the self-management ability, the level of mental health, and the compliance with treatment among patients with chronic diseases. The spirit of MI can be translated into five central principles summarized by the acronym DEARS and may be used for motivation of recipients:

Principles of Motivational Interviewing

Principle 1: Developing discrepancy enables the recipients to see that their present situation does not necessarily fit into their values and what they would like in the future. Change is motivated by a perceived incongruity between present behaviour and important personal goals and values.

Principle 2: Expressing empathy towards recipients shows acceptance and increases the chance of the facilitator and recipients developing a rapport. Empathy is simply the demonstration of a keen but neutral curiosity for the patient’s ideas and attitudes regarding all sides of the behaviour change being proposed (Glovsky, 2017). Acceptance enhances self-esteem and facilitates change. Skillful reflective listening is fundamental. The recipients’ ambivalence is normal.

Principle 3: Amplifying ambivalence is about recognizing and verbalizing where the recipient is “of two minds”. As the facilitator brings the ambivalence out into the open and explores the two sides the recipient is dealing with, the recipient is enabled to work through it, opening the door to change (Miller & Rollnick, 2013).

Principle 4: Rolling with resistance prevents a breakdown in communication between recipient and facilitator and allows the recipient to explore their views. The facilitator should avoid arguing for change or directly oppose resistance. Resistance is a signal for the facilitator to respond differently. New perspectives are offered but not imposed (Miller & Rollnick, 2013).

Principle 5: Supporting self-efficacy. If a recipient believes that they have the ability to change, the likelihood of change occurring is greatly increased. A person's belief in the possibility of change is an important motivator. According to Holstermann et al. (2009) self-efficacy is an intrinsic motivation which may influence cognitive ability and motivation, which will lead to success if the recipient possesses it.

Self-care Abilities

Self-care is a key component in the management of chronic disease, yet there are many barriers that interfere with a patient's ability to undertake self-care (Cameron et al., 2010). Self-care can be defined as the process of engaging individuals to take responsibility for managing aspects of their health and adopting behaviours that prevent disease, limit illness, and restore health (Jaarsma et al., 2009).

Rock et al. (2013) and Stamp & Chapman (2013) pointed out that patients with gout frequently have multiple co-morbidities, including hypertension, cardiovascular disease, renal impairment, diabetes, obesity, and hyperlipidaemia and in combination known as the metabolic syndrome. These multiple chronic conditions (MCC) are creating challenges for clients, families, and the health care system (Jaarsma et al., 2009).

Through their engagement and active participation in their management, recipients are empowered to have more control over their daily lives by purposely engaging in healthy behaviours, symptom monitoring and implementing a course of actions that can lessen debilitating symptoms from chronic ill health resulting from suffering from gout and care giving.

Making sure recipients are involved in and knowledgeable about their health is vital when addressing a chronic illness such as gout and its co-morbidities, and the ill-health of caregivers. Establishing self-management and communication between recipients and all members of the care team enables them to master the necessary self-care skills and improve their self-care behaviour that allows them to attain a satisfactory control. A high level of self-efficacy indicates high degree of effort to achieve behavioural change and behaviour maintenance, thus improving the self-care behaviour and changing the health outcome (Wu et al., 2013).

According to Hoffman (2013) in recent times there are greater numbers of people living with serious acute and chronic life-limiting illnesses. Consequently, the literature has indicated that symptom management is increasingly becoming the responsibility of many patients with complex chronic illness. The World Health Organization (WHO) advocates for symptom management interventions to enhance the quality of life, starting at the time of diagnosis and continuing throughout the chronic illness trajectory (WHO, 2011).

Evidence reveals that healthy behaviours such as effective symptom self-management can prevent or reduce much of the suffering from ill health conditions. The Theory of Symptom Self-Management (TSSM) is optimistic about the development of efficacy enhancing interventions for self-management, that it is critical to optimizing a patient's symptom self-management behaviors. The TSSM highlights the importance of clinical practice in incorporating interventions to increase a patient's perceived self-efficacy to optimize patient outcomes (Hoffman, 2013).

For patients, information is crucial to promote a sense of control, decrease emotional distress, support effective self-management, and eliminate disruptions of daily activities (Institute of Medicine, 2011). However, even with adequate information, not everyone has the same ability to manage their symptoms. Moreover, persons with chronic diseases report that the most distressing symptoms were those that they were least prepared to handle (Sun et al., 2012). Gout is a condition which comes with other chronic conditions, each with its own symptoms. Such a person may require distinctly different abilities to manage their symptoms, the success for which will require a person’s self-efficacy (PSE) (Bandura, 1997).

Also, the WHO endorses respect for a patient’s autonomy in making choices and taking an active role in developing his or her plan for symptom management (WHO, 2011). For those who are able, patients are autonomous and in charge of the important self-management decisions about their care, decisions on what and how much they are going to eat and drink, how long to rest, whether to exercise, and the extent to which they will take their medication or carry out other prescribed interventions. The searcher hopes that the developed self-management programme will address not *whether* or not clients will manage their symptoms, but *how* they will manage them.

Rosney et al. (2017) used the Powerful Tools for Caregivers (PTC) to measure any changes in caregivers’ self-care behavior, self-efficacy, management of emotions, and use of community resources after PTC classes. Caregivers reported an increase in their total time spent in performing stress management or relaxation techniques, with a subsequent increase in coping with the stress of caregiving.

Accordingly, the study showed a decrease in caregivers putting off going to the doctor, postponing regular check-up or examinations and cancelling or missing medical appointments. There was also less time spent feeling guilty or angry, and depressive while instead experiencing more periods of calmness and peacefulness. Furthermore, caregivers reported an increase in the usage of community resources: obtaining help with daily tasks, discussing with doctors, facility staff, family members and friends their needs and concerns related to caregiving. These findings suggest that the self-management programme could result in caregivers who take better care of themselves, who react to their emotions in a healthier manner, who are confident in their caregiving abilities as well as coping with the demands of caregiving, and who are more knowledgeable about receiving assistance from their community when necessary.

4.3.3 Context

The third aspect of the activity in practice-oriented theory is the context. Silverman (2010); George (2010) describe a context as the circumstances surrounding an event, statement, idea, situation, experience or an environment in which the activities were performed. Context refers to the relationships between the environment, personal factors and events that influence the meaning of a task, activity or occupation for the performer. These tasks, activities and occupations are typically part of daily life. They are usually called self-care, productivity and leisure (Brea et al., 2012).

The context for this programme refers to the accommodation of the clients and caregivers. The context is a domestic home in the community setting, the indoors and immediate surroundings of the household. The context is also described by Silverman (2010) and George (2010) as an environment where the data was collected about the experiences of adults suffering from gout and of their caregivers and where the training programme was implemented because the study was contextual in nature. The context where the data was collected in this study was discussed in Chapter 2 with the discussion on the research methodology. The context for this self-management programme refers to the optimal healing environment as shown in figure 4.4 below.

Figure 4.4: Context: Optimal Healing Environments (OHE). Adapted from: The Samueli Institute: (OHE) framework.

In its Optimal Healing Environments framework, the Samueli Institute defines healing as "a holistic, transformative process of repair and recovery in mind, body, and spirit resulting in positive change, finding meaning, and movement towards self-realization of wholeness, regardless of the presence or absence of disease." Cure, on the other hand, is defined as the elimination of disease or disease symptoms, in contrast to healing that can occur when cure is not possible. Using the OHE framework, adults suffering from gout as a chronic condition can find healing in the presence of gout and it concomitant symptoms. Sakallaris et al. (2015) contest also that there is universal agreement that a healing environment is desirable for clients and for caregivers.

4.3.3.1 Characteristics of an ideal context

An Optimal Healing Environment (OHE) stimulates and supports the inherent healing capacity of clients, families, and their caregivers. The potential for healing will be optimized by sound relationships in people, their health-creating behaviours, and the surrounding physical environment as well as the health institutions organizations. Each of the environments and constructs work synergistically to support and stimulate health creation and healing. (Sakallaris et al., 2015). The context must have a healing environment on all levels, namely, physical, psychological, spiritual and social, to ensure comfort, peace and dignity for all members.

Results from the study by Cho et al. (2016) suggest that certain interventions to enhance the accessibility of homes can have positive health and social effects. Home environments that lack accessibility modifications appropriate to the needs of their users are likely to result in people with physical impairments becoming disabled at home. They defined the accessible home environment as one which allows a person with functional limitations to get into and out of, and to circulate within the home, and to function independently.

There are four (4) identified optimal healing environments as depicted in figure 4.5 that would benefit the recipients of the programme:

Internal environment

Healing Intention: Adults suffering from gout and their caregivers and families need to consciously and purposefully direct their attention towards health, wellbeing and healing. The healing intention will be manifest in the care setting intentions, prayer, and assessing recipients' hopes and expectations for healing and incorporating those hopes into the plan of a self-management care plan.

Personal Wholeness: The congruence of mind, body, and spirit, experienced through relationship with self and others, will result in completeness and wellbeing. Mind-body-spirit congruence is enhanced through mind-body practices and interventions and attending to spirituality.

Interpersonal environment

Healing Relationships: Healing relationships are the connections between persons who hold an intention for healing to occur. Adults suffering from gout and their caregivers and families must strive to connect intentionally and conveniently so as to develop positive emotional engagements that will provide mutual benefits.

Healing Organizations: Healing organizations are driven by a mission to promote healing and health by providing appropriate structures—such as chronic disease clinics, including for gout, processes, and resources to stimulate and support healing through intention, relationships, person-centered and shared decision-making. Guided by their mission, healing organizations will optimize the potential for wellbeing of their adults suffering from gout and their caregivers and community as a whole.

Behavioral environment

Healthy Lifestyles: A healthy lifestyle for adults suffering from gout and their caregivers involves making choices in diet, activity, relaxation, stress reduction and sleep that create and maintain health. A healthy lifestyle is a way of life that optimizes potential for maximal healthy life years.

Integrative Care: Integrative care is team-based care that is person-focused and family-centered and incorporates multidisciplinary care providers at their highest skill level. Integrative care will address various health needs of adults suffering from gout and their caregivers, among others by enhancing self-care skills and ameliorating suffering.

External environment

Healing Spaces: Healing spaces incorporate evidence-based design and healing principles to optimize and improve the quality of care, outcomes, and experiences of patients and staff. Healing spaces as also suggested by Cho et al. (2016) will enhance the innate healing potential of adults suffering from gout and their caregivers.

Ecological Resilience: Ecological resilience restores the pathways of nature through supported healthy interactions with the physical environment. Nature is a key component of healing environments. The ability to integrate nature through gardens or views of gardens has been shown to reduce stress and improve the cohesion of mind, body, and spirit. Mindfully using resources positively, restoring green spaces, impacts human and planetary health. Advising adults suffering from gout and their caregivers about choosing chemical-free food not only restores farmland but also supports their health when eating the food.

4.3.4 Dynamics

The dynamics are the energy sources, purposes or motivation for the programme activities. The dynamics should be congruent with the socio-economic and cultural status of the patients to facilitate the achievement of self-management activities. The dynamics in this study were the health challenges in adults produced by suffering from gout and the health challenges in caregivers in the provision of care to the sufferers.

The dynamics which were arrived at were based on the storyline by adults suffering from gout and were holistic discomfort (physical and psychological), sense of dependency and of being a burden to others; and loss of relationships. On the other hand the storyline by caregivers centred on negative feelings (physically and emotionally); and social disconnectedness. The dynamics are shown in figure 4.5 as health challenges of adults suffering from gout and of their caregivers.

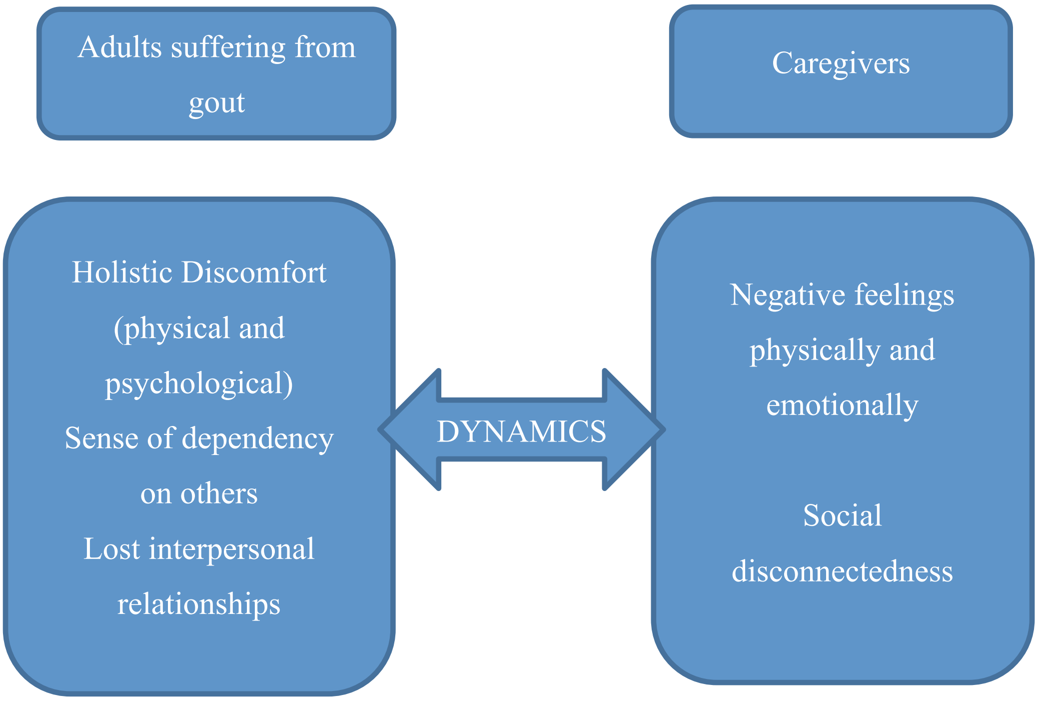


Figure 4.5: Dynamics: Holistic Discomfort (physical and psychological); Sense of dependency on others; and Loss of relationships; Negative feelings physically and emotionally; and Social disconnectedness.

Dynamics (the energy source of the activity) is the fourth aspect described by Dickoff et al., (1968) and is intended to work through the health challenges. The activities in this aspect would be: to deal with holistic discomfort (physical and psychological); work through issues of feelings of dependency on and of being a burden to others; create and maintain good interpersonal relationships thereby mitigating loss of social relations; explore and express negative feelings physically and emotionally; and reactivate the social network in order to minimize social disconnectedness.

4.3.4.1 Holistic discomfort (physical and psychological)

Gout has both physical and psychological ramifications, and a wide variety of intervention strategies can improve gout manifestations, as well as outcomes. Marks (2014) says thoughtful interventions are likely to impact gout disability outcomes quite favorably and significantly, regardless of disease type, duration or sociodemographic factors. These include monitoring and managing symptoms of the condition, including co-morbidities, pain-management, managing emotional consequences of suffering from chronic pain as well as dealing with disrupted sleep patterns and feelings of despondency.

The adults suffering from gout need to be advised to go for regular blood tests about once a month after starting daily treatment, to check that uric acid levels are low enough to prevent attacks and long-term problems (Finger, 2015).

In this context the co-morbidities each requires their own medications and each medication comes with its own side effects. Medicine compliance needs to be emphasized with each visit to a health facility (Rees, Jenkins, & Doherty, 2013).

4.3.4.2 Sense of dependency

There is a consistent link between self-efficacy, arthritis pain and disability (Cohen, 2014). The experience of chronic pain plagues an individual with decreased abilities to manage their day to day activities and life to their fullest, (Chowdhury, 2017) resulting in dependency on others. As a consequence of physical impairment the clients experienced increased levels of dependency on others. Many psychologists hold that low self-confidence and low self-efficacy have the power to limit an individual in all areas of life. They can hold one back in one’s career, facilitate dependency and prevent an individual from having healthy relationships, and even keep one disconnected from one’s inner power (Chowdhury, 2017).

Encouraging the adults suffering from gout to have an optimistic outlook on life and to engage in manageable activities will let them gain confidence. It brings positive change to one's mind, so that they can overcome their own problems successfully. Having a positive outlook enables one to cope better with stressful situations, which reduces the harmful health effects of stress on one’s body (Mayo Clinic Staff, 2017). It is important for the adults suffering from gout to shake off the feeling of being worthless, as if there is nothing left to give to others.

4.3.4.3 Lost relationships

Pain, by its nature, draws an individual away from friends, family, and personal interests, often leading to protracted suffering and isolation from activities that enhanced the patient's life. Being socially unconnected is influential for psychological and emotional well-being. The pain associated with recurrent flares in the adults suffering from gout is also responsible for facilitating poor social relationships (Chowdhury, 2017) and can also lead to reduced participation in social and recreational activities as patients seek to minimize the chance of precipitating a flare or being caught away from home when one occurs.

The experience of losing something valued is a part of life no one can escape from and one feels an empty spot within. One can learn to grow from the loss, and start taking steps to fill up the void, and replace the negative feelings with positive ones. By changing the negative self-talk, the adults suffering from gout will be able to reframe their expectations of life and themselves and to facilitate modifying their lifestyle to adapt to the circumstances.

4.3.4.4 Negative feelings

Stress and work life balance are often at odds with each other. Caregiving activities are quite more often than not, interfering not only with the mental, physical, and emotional health, but also with among others other formal commitments outside of the home, or your relationships with friends and family. Sleeplessness or insomnia is also a reality for many caregivers. A recent study showed that lack of sleep kills brain cells. There is no way to reverse the injury caused to your brain by prolonged sleeplessness.

It seems that an occupational hazard for caregivers is to give at the expense of their own health and wellbeing, the most common result being exhaustion (Elizz, 2016). Their mental or cognitive fatigue makes it difficult to think or feel, impacting the ability to complete tasks. The most appropriate advice to caregivers would seem to be to set a manageable pace. People seem deeply confused about the nature of negative emotions and how to process them, says Henriques (2017). There is a need in teaching caretakers how to understand their emotions and how to adaptively relate to and process them.

4.3.4.5 Social disconnectedness

Balancing living life with caregiving in daily life activities is essential to wellbeing. There are increasing levels of social loneliness and isolation, as seen in individuals tasked with caregiving. The "loss of self" with no opportunities to engage in the activities they value most may explain why caregivers' wellbeing is often affected. A person's activities and social connections in daily life seem to be highly related to his or her feelings of identity, and maintaining an acceptable sense of identity is essential to wellbeing. It is important for them to start taking care of themselves as caregivers, and changing some things about how they care for themselves and/or getting some support from family and friends. It is equally essential that they become aware of and understand the importance of work life balance.

4.3.5 Procedure

The procedure in this programme involved dynamic interaction between the agent and the recipients, the process during which knowledge and skills on how to take care of themselves, and techniques on how to develop confidence for the facilitation of self-management were discussed. Other information included skills on managing emotions and stressors. Figure 4.6 below shows the procedure for facilitating self-management:

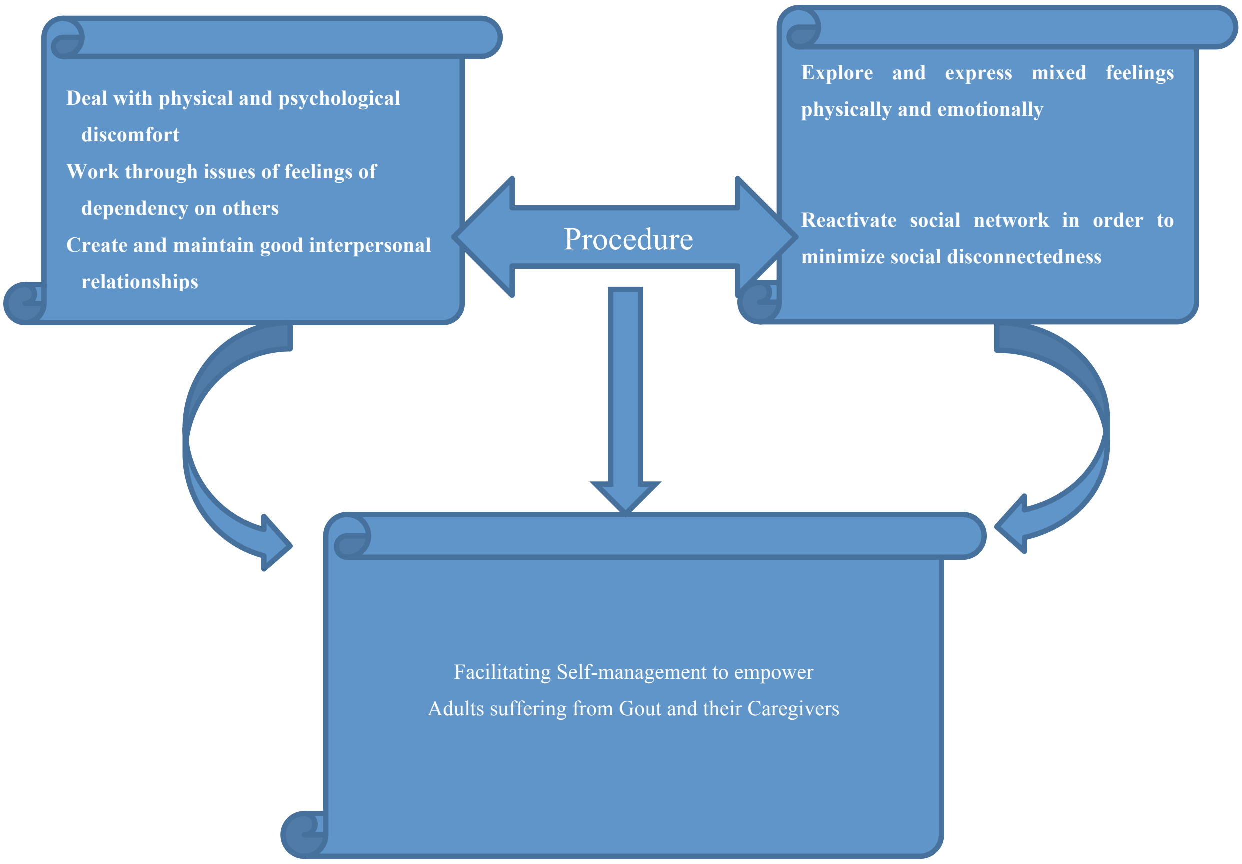


Figure 4.6: Procedure: Empowering adults suffering from gout and their caregivers in self-management.

The procedure for facilitating self-management focused on essential skills required to be able to execute self-management in a proper manner. Self-management includes the tasks that adults suffering from gout and of their caregivers must undertake to live well with health challenges produced by suffering from gout and in the provision of care to the sufferers as discussed under dynamics (The British Columbia (BC) Ministry of Health, 2011).

For a programme to be identified as a "self-management programme" it must teach patients a variety of essential skills as identified by Lorig & Holman (as cited by Reers, 2016).

4.3.5.1 Problem-solving

Problem solving is a core self-management skill, process that involves teaching patients basic problem-solving skills; these include problem definition and identification, generation of possible solutions—including the solicitation of suggestions from friends and health care professionals, solution implementation, and the evaluation of results. 'Solving problems' includes several steps, from defining the problem through finding possible solutions, to the final implementation of a solution and the evaluation of the solution (Lorig & Holman as cited by Reers, 2016).

According to Enguidanos, Coulourides, Keefe, Geron, and Katz (2011) the most commonly identified problems by patients included health-related issues such as the need for exercise or for weight loss activities, for medical care and medical equipment needs, and for gathering information on their medical condition. It would seem that problems identified by adults suffering from gout and their caregivers could more likely be solved than those identified by a health care professional. Using Problem Solving Therapy (PST) in primary care may facilitate adults suffering from gout and their caregivers in addressing key health and wellness issues.

4.3.5.2 Decision making

Adults suffering from gout and of their caregivers must make day-to-day decisions in response to their disease conditions, for example, how to know when one has exercised too much or not enough, how to know when a symptom is medically serious, or should one continue taking a medication? To do this, adults suffering from gout and of their caregivers must have the knowledge necessary to meet common changes, based on having enough and appropriate information. They need to be able to identify warning signals when caring for their symptoms, to have suitable guidelines to follow, and to make appropriate choices to manage their symptoms properly (Lorig & Holman as cited by Reers, 2016).

The best formula for making health decisions is to combine the most reliable medical facts with personal values. These include fears, lifestyle, and experiences, and they all play a role in helping with decision making about health. One is more likely to feel better about the chosen approach if it is the one best suited to one’s needs and values. Sometimes the best choice is to say "no" to care that one doesn’t need (Healthwise Staff 2016).

4.3.5.3 Resource utilization

It is important to teach them how to use resources effectively. It is better to gather as much information from as many sources as possible, rather than just obtaining information from one source. ‘Utilizing resources’ means that adults suffering from gout and of their caregivers do not only need to be given resources, but also need to know how to use them (Lorig & Holman as cited by Reers, 2016).

For the individual patient, the definition of value is deeply personal and depends on a person’s situation along life’s trajectory, how the individual views the potential benefits and harms of treatment options, and what the individual most wants to preserve (Lee, Hultman, & Sepucha, 2010). Brownlee et al. (2016) say that for patients, the single most important barrier to assigning value to a possible treatment is the failure of health care providers and manufacturers to ensure that patients have the information they need to make informed choices.

4.3.5.4 Patient–caregiver relationships

'Forming a patient-caregiver partnership' means that the patient should work with the caregiver as a partner (Lorig & Holman as cited by Reers, 2016). The caregivers, along with adults suffering from gout, have a responsibility not only to one another, but to their professional care team. It is vital to openly discuss the ground rules for this caregiver-recipient relationship.

Kaplan (2015) remarks that keeping information to oneself is often due to fear. The fear of conveying possibly frightening new symptoms or painful emotions can deter people from sharing intimate and important information, resulting in isolation and despair, well known to adults suffering from gout and their caregivers.

4.3.5.5 How to take action

The self-management skill of taking action is making a short-term action plan and carrying it out with confidence. The skill to 'plan actions' involves making short-term and realistic action plans (Lorig & Holman as cited by Reers, 2016) to manage a specific personal situation. To accomplish this skill, adults suffering from gout and their caregivers need the confidence to, for instance deal with medical management, role management and emotional management of their conditions.

4.3.5.6 Areas of coping skills. The procedure also focused on improving the physical health, psychological functioning, and social relationships of adults suffering from gout and of their caregivers as outlined by Swendeman et al. (2009).

4.3.5.6.1 Physical health

Physical health includes a framework for understanding illness and wellness; health promoting behaviours; treatment adherence; self-monitoring of physical status; accessing appropriate treatment and services; and preventing transmission. Health is when the body functions as it is supposed to function. Adults suffering from gout and their caregivers need nutrition and exercise, as well as sleep and rest to maintain their health. The main concerns in health are preventing disease and promoting health (Kurtus, 2017).

4.3.5.6.2 Psychological functioning

Elements related to psychological functioning include among others, self-efficacy and empowerment; cognitive skills; reducing negative emotional states; and managing identity shifts. Adults suffering from gout and their caregivers may experience a wide range of psychological responses including uncertainty about the future, anxiety and depressive disorders and avoidance of physical activity.

Any health challenges as experienced by adults suffering from gout and their caregivers induce acute illness stressors such as becoming aware of a disease diagnosis, undergoing burdensome treatment, experiencing a relapse, and threats to social relationships, all of which induce loosely coupled cognitive, emotional and behavioral responses. The cognitive, emotional and behavioral responses are hypothesized to interact and influence health outcome (Dekker & de Groot, 2016).

Figure 4.7 present the relationships in describing the main pathways in the process of psychological adjustment to chronic disease.

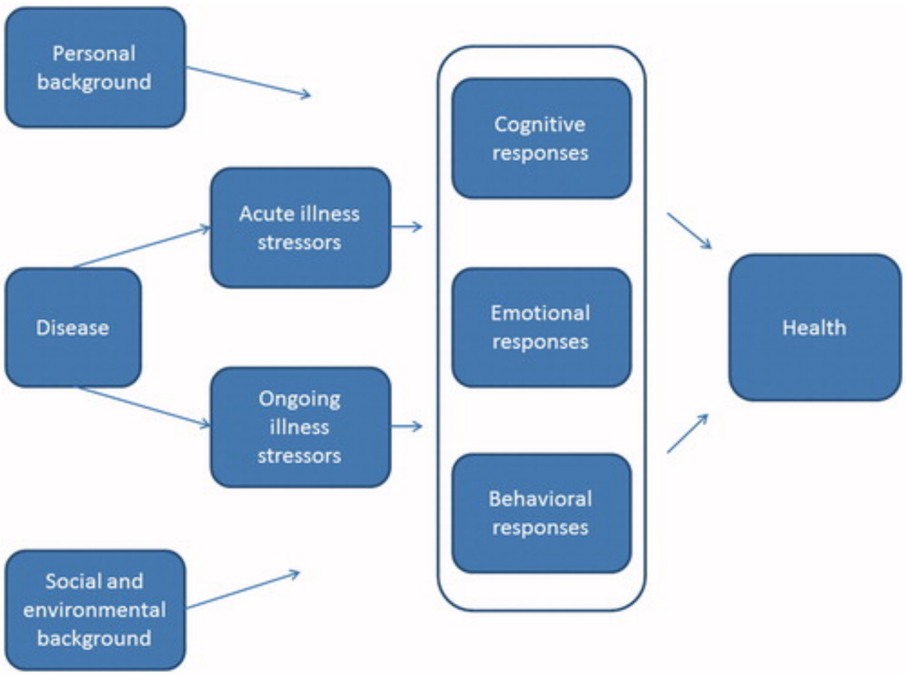


Figure 4.7: Schematic representation of psychological adjustment to chronic disease.

Acute and ongoing illness stressors induce cognitive, emotional and behavioral responses that influence health outcome. These responses are key elements in the adjustment process. Cognitive response leading to good health is self-efficacy, while wishful thinking is believed to lead to poor health. Engaging in good health behaviours such as physical activity is a behavioral response that may lead to good health, whereas avoiding physical activity is likely to result in poor health.

In summary, in the process of facilitating self-management in adults suffering from gout and their caregivers certain aspect need to be taken cognizance of. Psychological functioning, acute and ongoing illness stressors; emotional, cognitive and behavioral responses; personal background; and social and environmental background are all major categories in the adjustment process to chronic conditions or diseases.

4.3.5.6.3 Social relationships

Social relationship is of utmost importance for better health outcomes for adults suffering from gout and their caregivers. The idea of sharing, partnership, interdependency implies collective action oriented toward a common goal—in this case, improving the quality care and safety of adults suffering from gout and their caregivers (Stephen, 2015).

4.3.6 Terminus

With regard to this study, terminus denotes the desired outcomes as a self-management aptitude which encompasses knowledge, skill and confidence in dealing with health challenges as discussed under point 4.3.4 (dynamics) as a result of the learning experiences developed by the adults suffering from gout and their caregivers.

Below in figure 4.7 the terminus depicts techniques that an empowered person will display as the end results of the self-management programme.

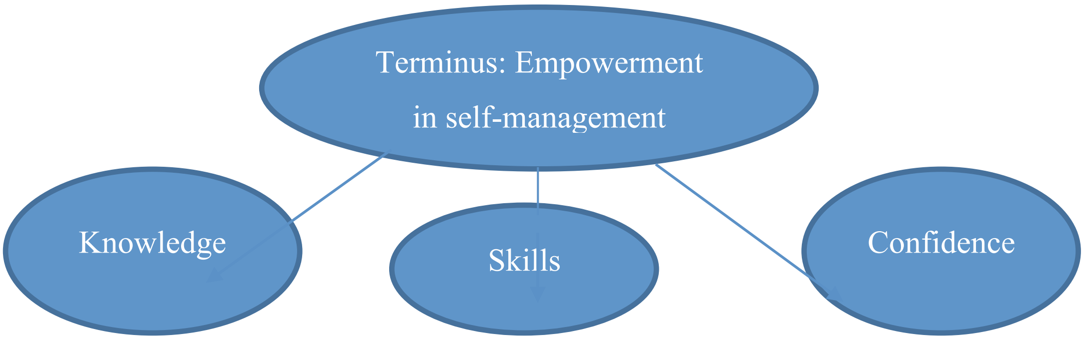


Figure 4.8: Terminus: Empowered adults suffering from gout and their caregivers

The programme aimed at empowering adults suffering from gout with knowledge and skills to deal with problems associated with suffering from gout such as dealing with physical and psychological discomfort, modifying lifestyle - including healthy eating, appropriate exercise and appropriate use of medications, and communicating effectively with family, friends, and health professionals or caregivers. On the other hand, techniques to deal with problems associated with caregiving challenges such as how to mitigate negative emotions and to reconnect lost relationships were geared to empower the caregivers.

It is worth noting that self-management is the fundamental concept in the programme as stated by Richard and Shea, (2011, p. 261). They assert that self-management is "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions". This ability requires knowledge and skills and going along with acquiring knowledge and skills to manage health challenges is the element of confidence to use these techniques to make lifelong changes to health, without relapsing to the earlier unhealthy habit.

4.3.6.1 Taking ownership of health needs and becoming an expert

Schulman-Green et al. (2012) identified three themes of self-management processes: focusing on illness needs, activating resources, and living with a chronic illness. It is envisaged that adults suffering from gout and their caregivers will be well equipped with these expertise.

Tables 5.1, 5.2 and 5.3 illustrate how each of these processes underlies the tasks and skills. Short discussions on these themes will follow after each table.

Table 5.1: Focusing on illness needs

Processes	Tasks	Skills
Learning	Learning about the condition and health needs	Acquiring information Learning regimens, skills and strategies
Taking ownership of health needs	Recognizing and managing body responses	Monitoring and managing symptoms, side effects and body responses Recognizing limits Adjusting treatments and regimen to manage symptoms and side effects
	Completing health tasks	Keeping appointments Managing/taking medications Performing treatments and keeping up with changes in one's regimen
	Becoming an expert	Goal setting Decision-making Problem-solving Planning, prioritizing and pacing Knowing if/when to take a break from one's regimen Developing confidence and self-efficacy Evaluating effectiveness of self-management
Performing health promotion activities	Changing behaviours to minimize disease impact	Modifying diet, nutrition, smoking and physical activity Reducing stress Taking action to prevent complications
	Sustaining health promotion activities	Keep up with screenings and lifestyle modifications Using complementary therapy

4.3.6.1.1 Focusing on Illness Needs

The process of Focusing on Illness Needs can be performed solely by the individual, or by the individual in conjunction with family members and healthcare providers, depending on the individual's needs, values, resources, and other situational variables. As part of this process, the adults suffering from gout and their caregivers learn about the chronic illness, take ownership of their health needs, and perform health promotion activities, ultimately becoming an expert.

Stork (2010) believes that helping patients become the "CEO of their own health," is about enlightening individuals on simple ways to attain and maintain good health based on their own life and circumstances and teaching people how to prevent illness before it happens. Most people don't realize that they make 200-plus health-related decisions every day that dictate how well and how long they live. Stork (2010) believes good health is achieved by focusing on those seemingly inconsequential decisions that people make throughout the day.

Table 5.2: Activating resources

Processes	**Tasks**	**Skills**
Healthcare resources	Creating and maintaining relationships with healthcare provider(s)	Finding the right provider(s) Communicating effectively Making decisions collaboratively
	Navigating healthcare system	Coordinating services/appointments, insurances Using resources effectively Creating and revisiting advance care plans
Psychological resources	Identifying and benefiting from psychological resources	Drawing on intrinsic resources, e.g., creativity Drawing strength and wisdom from past experiences Cultivating courage, disciplines and motivation Maintaining positive outlook and hope Maintaining self-worth Advocating for self
Spiritual resources	Sustaining spiritual self	Acknowledging a higher power Nurturing the spirit, Praying Being part of a spiritual community
Social resources	Obtaining and managing social support	Seeking support from family and friends Being proactive to limit isolation Creating a community of peers with similar experiences Working through issues of dependence/independence Assisting others to become partners in disease management (e.g., distributing tasks)
Community resources	Addressing social and environmental challenges	Seeking resources such as • financial assistance (prescription subsidies) • environmental support (supportive devices) and • community resources (transport)

4.3.6.1.2 Activating Resources

Resources are integral to optimum self-management. Activation of resources may vary in intensity and complexity depending on the illness and the role that the individual can assume in managing the illness. Although self-management is an interactive process, individuals vary in their ability and willingness to take on a role, or to let others play a role, in management of their illness.

Identifying the specific resources that an individual chooses to activate is a personal process that can vary over time as they create a structure of resources, as they optimize their self-management skills, and as their illness and subsequent needs change. The structure of the health care delivery system includes how, where, and when care is made available, as well as policies regulating reimbursement for different types of care, and whether patient preferences for care are valued (Centers for Medicare and Medicaid Services 2013; James, 2013).

Table 5.3: Living with a chronic illness

Processes	**Tasks**	**Skills**
Processing emotions	Processing and sharing emotions	Exploring and expressing emotional response Dealing with shock of diagnosis, self-blame, and guilt Grieving
Adjusting	Adjusting to illness	Making sense of illness Identifying and confronting change and loss (changes in physical function, role, identity, body image, control and mortality) Managing uncertainty Developing coping strategies (self-talk) Dealing with discouraging setbacks Focusing on possibilities (envisioning the future, reframing adversity into opportunity) Accepting the “new normal”
	Adjusting to “new” self	Clarifying and establishing roles Examining health beliefs Making social comparisons Choosing when and to whom to disclose illness Dealing with stigma
Integrating illness into daily life	Modifying lifestyle to adapt to disease	Reorganizing everyday life Obtaining assistance with activities of daily living Creating a consistent health routine Controlling environment Being flexible
	Seeking normalcy in life	Carrying out normal tasks and responsibilities as much as possible Managing disruptions in work, family, and social activities Balancing living life with health needs Finding new enjoyable activities
Meaning - making	Re-evaluating life	Reflecting on/rearranging priorities and values Reframing expectations of life and self Coming to terms with terminal conditions and end of life
	Personal growth	Learning personal strengths and limitations Becoming empowered Being altruistic
	Striving for personal satisfaction	Finding meaning in work, relationships, activities, and spirituality Creating a sense of purpose Appreciating life

4.3.6.1.3 Living with a Chronic Illness

Living with a chronic illness is a self-management process that includes tasks and skills related to coping with the illness and growing as a person, as well as to transitioning from a focus on the illness needs to integrating the illness into the context of the individual's life.

Meaning-making refers to the individual's efforts to determine the meaning of the illness in one's life, and describes the tasks and skills of reevaluating life, personal growth, and striving for personal satisfaction. It is possible that there is a temporary aspect to these processes where emotional processing must to some extent precede adjusting, which must in turn precede meaning-making; however, these processes are likely to overlap and interact with each other.

Bernhard (2015) has this to say: “What makes us miserable is not awareness of our present moment’s experience, but aversion to it.” Practicing mindfulness (which I define as caring attention to our present moment experience) can help ease both physical and mental suffering. The three components of physical discomfort are the unpleasant physical sensation itself; our emotional reaction to it (aversion in its many forms, such as anger or frustration); and the stressful thoughts we spin that have no basis in fact (“I’ll be in terrible pain for the rest of my life”). Note that two of those three components that comprise our experience of bodily discomfort are mental in origin!

Mindfulness can help us learn to catch stressful emotions when they first arise, so we can mindfully note their presence and turn our awareness to self-compassion instead of launching ourselves into those stressful stories. As many Buddhist teachers have said, “The suffering is in the stories.”

4.3.6.2 Summary of the above discussion

The processes of focusing on illness needs, activating resources, and living with a chronic illness, encompass physical, psychological, social, spiritual, existential, and system-related processes, reflecting a more holistic picture of self-management. The actual experience of self-management is ongoing and dynamic, with overlapping processes, tasks, and skills. McCorkle et al. (2011) give an example of an individual living with rheumatoid arthritis who is attempting to reorganize everyday life to accommodate pain and affected functioning (identified as part of living with a chronic illness), who may simultaneously have to prioritize work and family activities to ensure adequate daily rest (identified as part of focusing on illness needs).

The processes of self-management do not appear to be linear. An individual does not necessarily progress from a focus on illness needs, to activating resources, to successfully living with a chronic illness. Giving an example to this effect, Schulman-Green et al., cited in Livneh & Antonak , 2012) states that a new diagnosis of a chronic illness may require an initial focus on illness needs for one individual, while another may need to explore and express emotions before focusing on illness needs. Thus, there is considerable individual variation in how or when processes of self-management are prioritized and undertaken.

4.4 Summary

This chapter discussed the conceptualization of the study findings according to the survey list of practice theory by Dickoff et al. (1968) in order to capture the framework that formed the basis of the development of a self-management programme. The programme was developed to facilitate empowerment of adults suffering from gout and their caregivers in the Omaheke region by developing knowledge, skills and confidence that would to help them manage the health challenges more effectively. The survey list included the applicable concepts of:

The agent denoted the researcher who acted as the facilitator and developed the self-management programme. The agent needed some facilitating characters to enable her to connect with the recipients of the programme to make it acceptable to them.

The recipients of the self-management programme were the adults suffering from gout and their caregivers, who acquired knowledge, skills and confidence to manage their own health challenges thereby improving the quality of life.

The context was the domestic homes in the community setting where the adults suffering from gout and their caregivers were living, which was characterized by compassion and love, and awareness of interconnectivity portrayed by listening and communication skills that foster trust and a bond among the household members and health providers. The intention, expectation and belief in healing facilitated the practice in health promotion behaviours that changed lifestyle to support self-healing.

The procedure involved dynamic interaction between the facilitator and recipients in information sharing, discussions and demonstrations that covered specific content related to acquiring knowledge, skills and confidence on how to take care of themselves and for the caretaker including skills on how to manage emotions and stressors.

The dynamics in this study entailed holistic discomfort, feelings of dependency on others, and loss of relationships on the part of adults suffering from gout; and negative feelings physically and emotionally and social disconnectedness on the part of the caregivers.

The terminus refers to the end results envisaged in the development of this self-management programme. The envisioned results were the knowledge, skill and ability to confidently deal with health challenges caused by suffering from gout and from provision of care.

In the next chapter the programme development will be discussed by describing the structure and process of the guidelines; and guidelines will be provided for operationalization of the guidelines in practice.

CHAPTER 5: A SELF-MANAGEMENT PROGRAMME DEVELOPMENT

5.1 INTRODUCTION

Chapter 4 provided phase 2, a description of the development of the conceptual framework according to the guidelines proposed by Dickoff et al. (1968), whereby classification of central concepts and related concepts were discussed. The three essential ingredients of a conceptual framework were discussed, namely the goal content, prescription of the activity and a survey list. The six elements of the survey list outline encompass the agents, recipients, context, dynamics procedures, and terminus as discussed in Phase 1.

Phase 3: Programme development

This chapter, as Phase 3, involved the development process of the programme to facilitate self-management by adults of suffering from gout and their caregivers at home. The final part of this phase discussed the content for self-management programme. The analysis conducted on the data collected from the unstructured individual in-depth interviews with adults of suffering from gout and with their caregivers, and the focus group discussion with their caregivers in Phase 1 and the conceptual framework as described in Chapter 4 (Phase 2) contributed to the development of the programme.

The results of the data analysis (Chapter 3) and the formulation of the conceptual framework made it possible to develop the programme on the basis of the needs that emerged from the themes. The outcome of this process was key themes and sub-themes as summarized in Table 3.1.

The purpose of this chapter was to delineate processes of self-management, with emphasis on the healthy lifestyle behaviours to be undertaken by individuals in order to help direct interventions and improve health outcomes for adults suffering from gout and their caregivers; also for optimal growth and development, or the preventive strategies performed to promote or to maintain health (Richard & Shea, 2011).

5.2 The Science of Self-Management

Nursing science contributes to the field of self-management of chronic diseases through research that defines the concept, describes its theoretical underpinnings, and develops and examines the effectiveness of self-management interventions in various settings. A group of nurse scientist leaders assembled to discuss "The Science of Chronic Illness Self-Management" as the topic of the 2013 National Nursing Research Roundtable (Grady & Gough, 2014).

As a concept, self-management has been described as the day-to-day management of chronic conditions by individuals over the course of an illness, to suggest that patients are active participants in their own treatments. Conceptual and theoretical descriptions of self-management with reference to components, processes, and outcomes, 3 sets of tasks associated with the work of living with a chronic illness, such as gout were identified (Corbin & Strauss as cited by Grady & Gough, 2014). The tasks included:-

- Medical management of the condition, which focuses on treatment of an acute attack of gout, including using anti-inflammatory medicine and long-term urate lowering treatment to prevent recurrent attacks of gout and rest. Bernal, Quilis, Andrés, Sivera, and Pascual (2016) advise that to ensure treatment adherence it is necessary to explain to the patient what the objectives are.

- Behaviour management relating to lifestyle modifications to prevent recurrence includes eating fewer high-purine foods (e.g., red meat, offal, and shellfish), drinking less alcohol and eating more low-fat dairy products and vegetable sources of protein, in combination with a programme of moderate exercise (Zhu et al., 2011).
- Emotional management which shares the management of pain, as pain does not just affect the body; it also affects how people feel emotionally. Calming the mind and body by practicing meditation can help direct and distract the mind away from a focus on pain. Regular physical activity relieves depression and anxiety. When happy and positively focused on happy memories one may hardly notice the aching fingers.

More about emotional support is that according to Heath (2017) studies have shown that patients reported needing more emotional support than any other kind of social support including physical, intellectual, spiritual, financial, and practical support. The researcher in the context of this study is convinced that it is appropriate to address the concept of emotional intelligence, which is defined as an awareness of your actions and feelings, and how they affect those around you. It also means that you value others, listen to their wants and needs, and are able to empathize or identify with them on many different levels. It also involves your perception of others: when you understand how they feel, this allows you to manage relationships more effectively (The Economic Times, 2018).

5.3 Theoretical Approaches Integrated into the Development of the Programme

The development of the programme was based on the needs that were identified during the situational analysis in Phase one (1) of this study. In view of the fact that the purpose of the programme was to educate and train the participants who are adults to manage the condition of suffering from gout and for their caregivers to assist and support them in challenges that come with caring, different instructional methods were used in facilitation of learning and teaching, based on the concept of five teaching strategies for adults. Through utilizing a “lived body” paradigm and drawing upon qualitative data gathered from interview with patients with multi-morbidities, Pickard & Rogers (2012) came to describe the practice of embodied self-awareness in health and illness and the experiential knowledge and embodied processes (cognitive, corporal and social) as forming foundation of “chronic illness work”. This theory has the same perception of self-management as the frameworks of chronic disease self-management (CDSM). The researcher therefore adopted these approaches taking into account the participants’ learning needs and their desire and aspiration towards learning new topics or content in the self-management context.

As was alluded to in Chapter 1, the three approaches, namely the philosophical approach, the educational approach and the chronic disease self-management approach, were discussed in detail. The discussion started with the first approach being the Philosophy of Person-centered Care.

5.3.1 Philosophy of Person-centered Care

The fundamental concept in the development of this programme is self-care as part of self-management. Authenticating cognitive practices, focusing on improving self-efficacy and imparting general coping strategies, better breathing and healthy eating, improved communication and working with health-care professionals, logical and autonomous decision-making are all intended to inculcate an ideal typical late-modern patient: responsible, self-directed and managing their own health Rogers (2009). Self-care in the context of multi-morbidities, and particularly data detailing the interplay between embodied practices of self-care and primary care interventions, present a challenge to clinical care; and self-care in the context of multi-morbidities is more challenging than in the context of single conditions (Pickard & Rogers, 2012).

When conceptualised within a broader agenda of ‘engaged and active patients’ such expertise is expected to relieve resources significantly. A new policy focus on patient chronic illness and self-management has officially given attention to managing long-term conditions and has placed patient action at the core of the work of participating with personal illness management. Calnan & Gabe (2009) hypothesize that the way to develop patients as experts is through the increased involvement of active and informed patients in health-care decision-making and self-management in primary care.

According to Toombs (2001) illness disrupts the usual phenomenological anatomy. One becomes conscious of one’s body or part(s) of one’s body in a way that it appears disfigured and which disrupts practices, roles and relationships. This could also be the case with the adults suffering from gout as this condition affects mostly the joints and disfigure them. Henceforth, a need was identified to develop a self-management programme so as to empower the participants with the knowledgeo manage their health condition.

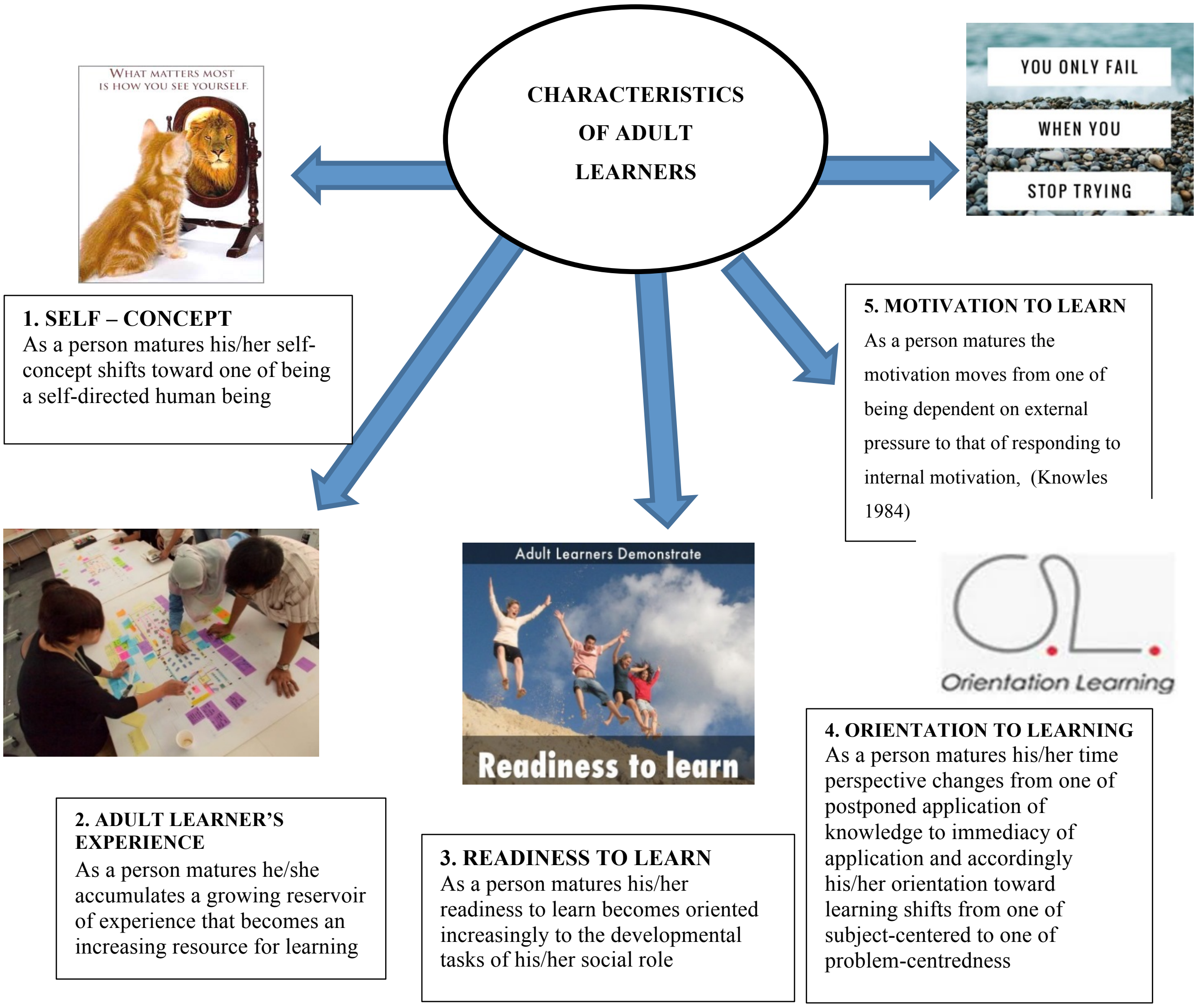
5.3.2 Programme Description

The interventions adopted in the development of this programme were an interactive style based on the participants’ experiences and previous knowledge and skills required to carry out the tasks of self-management and caring. These techniques responded to the adult learning needs of the participants by making the learning activities more interesting, as emphasized by the proponents of adult learning. To cater for their chronic conditions the self-management programme was also developed within the frameworks of chronic disease self-management (CDSM). As a starting point the principles of adult learning as indicated in Knowles's andragogical learning theory were used, followed by the frameworks of chronic disease self-management.

5.3.2.1 Knowles's andragogical learning theory

The development of the self-management training programme adopted Knowles' theory (1996) in which the learning and teaching methods were advanced in line with the learning needs of the adult participants.

Adult learning is a theory that holds that adults prefer learning in situations that consider and incorporate the concept of five teaching strategies for adults; that the motivations to learn evolve as one becomes older, complemented by self-directed learning (Taylor & Hamdy, 2013). Knowles explains that learning is influenced by the characteristics of learners as well as differences between adults and children in the way they approach learning. The characteristics of adult learners are depicted in Figure 5.1.



CHARACTERISTICS
OF ADULT
LEARNERS

1. SELF – CONCEPT
As a person matures his/her self-concept shifts toward one of being a self-directed human being

2. ADULT LEARNER'S EXPERIENCE
As a person matures he/she accumulates a growing reservoir of experience that becomes an increasing resource for learning

3. READINESS TO LEARN
As a person matures his/her readiness to learn becomes oriented increasingly to the developmental tasks of his/her social role

4. ORIENTATION TO LEARNING
As a person matures his/her time perspective changes from one of postponed application of knowledge to immediacy of application and accordingly his/her orientation toward learning shifts from one of subject-centered to one of problem-centredness

5. MOTIVATION TO LEARN
As a person matures the motivation moves from one of being dependent on external pressure to that of responding to internal motivation, (Knowles 1984)

Figure 5.1: Characteristics of adult learners

The next discussion will focused on how these characteristics could be applied for teaching adults as suggested by Palis and Quiros (2014) and Lohman (2016). The suggestion was based on Knowles' andragogical learning theory principles, which are relevant to this study as will be summarized in explaining how to use these principles for effective instructions for teaching adult participants effectively.

Address the desire to know why something should be learnt: As adults in the self-management programme, the expectations and needs of adults suffering from gout and their caregivers were assessed. These allowed for appropriate selection of subject matter, in order to avoid the mistake of teaching content so basic that they already know it, or they find it irrelevant to their needs which could be viewed as a waste of time. Next was the introduction of the purpose and objectives at the beginning of the presentation—what they will be able to know or do with the knowledge acquired during the presentation. This step referred to the management techniques of dealing with the challenges that they faced with suffering from gout and from taking care by the caregivers. An outline at the beginning of the presentation gave them a preview of how learning will be conducted, what learning will occur and why learning is import. Bringing out the personal benefits of learning prompted the participants to assume an active role in deciding on challenges that needed to be addressed, while the implementer simply facilitated the learning.

Make learning practical and relevant: Adults will be motivated to learn as long as they perceive the learning as useful to help them perform tasks or solve problems they face in their lives. Dealing with suffering from gout and having to care for gout sufferers require a great deal of performing activities that are challenged by immobility and that require problem solving skills to mitigate negative emotions. They will learn more effectively when new knowledge, skills, attitudes and values are presented in the context of their application to real life situations. The concept of orientation to learning implies that the content of lectures should be relevant to what learners need to cope with in their daily practice. The experiences on suffering from gout and on caregiving presented through personal stories or cases added to the relevance that the audience found in the content. They provided authentic learning experiences and immediate real-world applications.

Active participation in class was used as part of a varied set of teaching methods: Active participation is any activity that engages students in doing things and thinking about the things they are doing. Encouraging active learning over passive learning is one strategy for helping students make a transition from dependent to self-directed learners. Adults are believed to have the self-concept of being responsible for their own decisions and their own lives and consequently they need to be considered by others as capable of self-direction. Discussions, case-based methods and debate were among the favoured methods used during presentations. Working in groups facilitated interacting and playing with others about ideas which made social interaction part of the learning process, with the goal of producing shared learning. The facilitator tapped into the participants' interest in solving problems, especially practical ones. Active listening was encouraged by questioning and invitations to contribute either through verbal expression or written expression, with the goal of producing shared learning, and structured opportunities for them to talk and reflect on during the presentation was provided. Participants were given notebooks and pens for taking notes to refer between discussions. Meanwhile the facilitator took responsibility for becoming a good observer of student participation.

Use adult learners' previous experiences and knowledge effectively*:* Adults come to learning situations with accumulated experience. By honouring the life experiences they bring to the learning situation and acknowledging their experiences, adult learners will feel respected. Adults prefer to be respected and are motivated to learn when they feel accepted and equally accommodated, and when their potential and contributions are valued and acknowledged. Adults are believed to have the self-concept of being responsible for their own decisions and their own lives and consequently need to be considered by others as capable of self-direction. These aspects of recognition encourage active learning and self-directedness and falls aptly with the statement by Baumgartner (2011) that self-directed learning is central to coping with chronic illness. Self-directed learners are able to control, motivate, supervise and adjust their own learning (Roberts, Gustavs, & Mack, 2012). It is important to tap into that wealth of wisdom of the participants whenever it is appropriate, using techniques that take into consideration their experience. Additionally, constructivist learning theories suggest that new information must connect to previous knowledge in order to be understood, retained and then utilized.

Match teaching content to the patient’s current stage of readiness to learn: Adults are ready to learn what they need to know to cope with the situations they face in their real lives. This principle supports the relationship between the content to be taught and the learner's ill-health circumstances that are changing. Anything, including gout, that affects physical or psychological comfort such as pain, fatigue, anxiety, or fear can affect a person’s ability and motivation to learn for better outcomes.

5.3.2.1.1 Readiness to learn as applied to behavioural change

Behaviour has been defined as ‘anything a person does in response to internal or external events’ (Hobbs et al., 2011); therefore, according to Adamson and Benelam (2013) by implication, ‘behaviour change’ requires a change in response to those internal or external events. It is imperative for the adults suffering from gout and their caregivers as well as the facilitators to understand that behavioural change is a challenge people face and is by its nature a difficult journey; it seems difficult for people to initiate and sustain the behaviours that would reduce the risk of relapsing into the old behaviour (Stubbs & Lavin 2013). Environments and programmes that support, nurture and facilitate long-term behaviour change give people the capability, the opportunity and the motivation to navigate to a healthy lifestyle (Stubbs & Lavin 2013).

5.3.2.1.2 Stages of behavioural change

Zimmerman, Olsen & Bosworth (2000) identified five stages (now condensed to three stages by Daivadanam, Wahlström, Ravindran, Thankappanand, & Ramanathan (2014) in behavioral change. One may cycle through different stages several times before change is fully established. Identifying an individual's stage of change allows the facilitator to individualize the education and intervention that is most suited to that individual for that time. The aim is not to force the adults suffering from gout to change their behaviour but to help them move along the stages of change. Motivational interviewing (MI) techniques are most effective at all stages. Assessing an individual's readiness for change allows individualized strategies, making effective outcomes more likely. The conceptual model of behavioural change as depicted in figure 5.2 consists of three (3) stages, each with its elements:

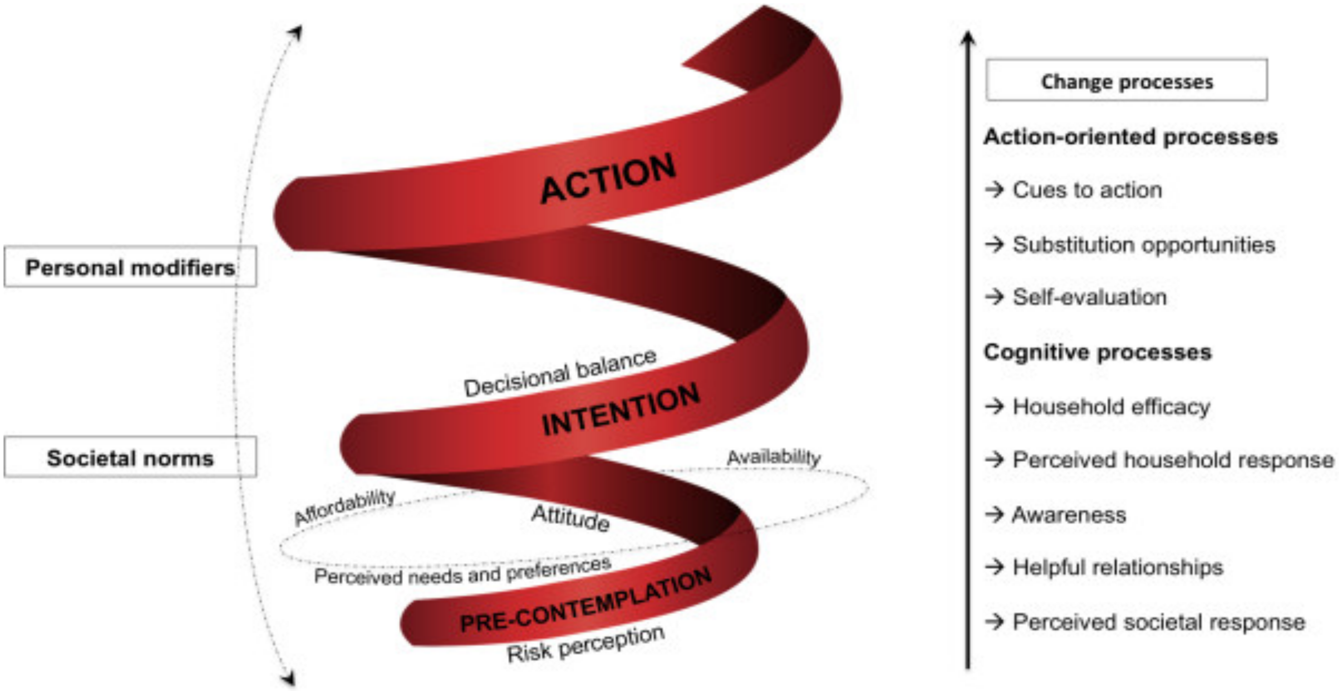


Figure 5.2: Conceptual model of behavioural change (Sourced from Zimmerman, et al., 2000**).**

The central three-stage spiral represents the three stages of change:

Pre-contemplation: At this stage an individual is not thinking about change or does not intend to take action in the foreseeable future, they may be under-informed, in denial or have tried unsuccessfully so many times they have given up. The goal for the adult suffering from gout at this stage is to be sensitized to begin to think about changing identified risky behaviours that may trigger the gout attacks.

Intention (contemplation + preparation): The individual is now aware that a problem exists and intends to take action in the immediate future, and is preparing to make a specific change. The person might be ambivalent about changes, may feel a sense of loss despite perceived possible gain, or is weighing up benefits, and other things. The facilitator needs to assess barriers such as time, expenses, hassles and fears, and too amplify the benefits of change and consider possible strategies to overcome such barriers. Meanwhile, the caregiver should encourage the client to address barriers to full-fledged action, continuing to explore their ambivalence.

Action (action + maintenance): Having gone through the above exercise successfully, the adult suffering from gout is more aware of the pros and cons; and has already taken some significant steps in a positive direction, such as modifying their environment, making specific overt modifications in their life-styles and other risk factors to change and address the problem or being engaged to prevent relapse. Relapse is a normal part of the process whereby the patient may feel demoralized. The goal is to support the patient and re-engage their efforts in the process of change. This requires considerable commitment of time and energy, and motivational interviewing would be appropriate at this stage.

The 'impact factors' along the stem of the spiral:

Risk perception or perceived seriousness refers to judgment as to the seriousness or severity of the health problem of gout or of risky behaviour. Perceptions of disease risk play an important role in motivating people to adopt healthy behaviours (Dillard, Couper, & Zikmund-Fisher, 2010). Higher perceived risk is associated with greater cooperation and with more information seeking and greater desire for decisional involvement.

Attitude refers to the degree to which an individual has a favourable or unfavourable evaluation or appraisal of the behaviour in question. Attitudes can change to match behaviour. People may actually alter their attitudes in order to better align them with their behaviour (Cherry, 2018). Cognitive dissonance is a phenomenon in which a person experiences psychological distress due to conflicting thoughts or beliefs. In order to reduce this tension, people may change their attitudes to reflect their other beliefs or actual behaviours.

Decisional balance is defined as weighing of the pros (advantages) and cons (disadvantages) of changing behaviour. Changing behaviours involves a personal inventory of the advantages and disadvantages (decisional balance) associated with changing the behaviour, and decisional balance has been shown to be a valid predictor of progression through the different stages of change (Gazabon et al., as cited in Gullette et al., 2009). Decisional balance may relate to the opinion of adults suffering from gout in terms of the value or usefulness of a new behaviour in decreasing the risk of worsening gout or co-morbidities in terms of the expected costs and benefits.

The 'change processes' on the right side of Figure 5.2 enable progress from one stage to the other:

Action-oriented processes

Cues to action include events, people or things that prompt a desire to change behaviour. Without a planned intervention, people will remain stuck in the early stages due to lack of motivation to move through the stages (Communication for Governance, 2010). It is therefore of importance to provide for opportunities to substitute healthier behaviour for unhealthy or problem behaviour. Arranging for self-evaluation for cognitive and emotional assessment of an unhealthy behaviour might open possibilities and potential avenues for bringing about a change in the said behaviour.

Cognitive processes

Self-efficacy is the belief or confidence in one's ability as a person to control their behaviour and bring about a change or cope with different situations without relapsing to the earlier unhealthy habit. This confidence ties up with the perceived own response which includes perceived willingness (or consent) to participate in a behaviour-change intervention. Going along with these processes is the level of cooperation expected from the caregiver and other household members for such an endeavour.

Awareness, the knowledge about health risks and the benefits of different health practices, about the causes, consequences and solutions for a particular problem behaviour, can be greatly supported by helpful relationships. These types of relationships can promote caring, trust, openness, acceptance and support for the healthy behaviour change. Outside resources such as support groups, counsellors, or friends can also offer advice and encouragement (Cherry, 2018).

As an element of distraction during the change journey is the perceived societal response. Such social pressure could cause a person to perform or not to perform a particular behaviour. Social pressure often causes people to change their picture of reality, and those who resist it become emotionally upset (Dobrin, 2014). Fitting in feels good, even at the expense of a person's otherwise good senses. The quest for fitting in is this kind of pressure that mostly would trigger relapses.

The background factors, on the left of the figure, that act at all stages:

Personal modifiers (factors) are characteristics that influence personal perceptions, such as culture, education level, personality, sense of control, values, goals, felt responsibility, age, gender, chosen activities and past experiences (Gifford & Nilsson, 2014). Societal norms (factors) refer to socio-economic status and other higher hierarchical power structures in the household and community that influence behaviour. The social factors include religion, norms, social class, and cultural variations (Gifford & Nilsson, 2014). Adults suffering from gout who possess knowledge about the predisposing factors of the disease are likely to behave in ways that are conducive to healthy living. Social class, norms and households will also have an influence on whether the individual will stick to the behaviour change process.

The overarching influence is represented by the transverse plane between the first two stages (pre-contemplation and intention):

Perceived needs and preferences are special needs and preferences of the caregiver and other household members. If the interventions for behaviour change are not in line with the preferences of household members—for example, food type, taste, habit and household routines—then there would be little chance of success.

Availability and accessibility are a combination of availability of commodities, which includes physical access; if these are not in place it would increase the potential to make households resistant to the change process.

Affordability includes all the costs associated with accessing foods. If the affordability was basic or absolute, when even basic needs were taken care of with difficulty, then behaviour change strategies would be unlikely to have any impact if not accompanied by measures like financial support or any other support.

5.3.2.1.3 The 5 A's of behaviour change model

Behavioural support is an important part of any change attempt and should be recommended for all individuals who intend to engage in behaviour change. The 5 A's comprise a manageable evidence-based behavioural intervention strategy that has the potential to improve the success of an intention for behaviour change within a homebased setting.

The 5A's (assess, advise, agree, and assist, arrange) can guide the process of counselling an adult suffering from gout about behaviour change. The 5A's are discussed below:

- During the assessment stage, asking questions will elicit important information, and will help in making a link between lifestyle and health concerns. It is important not to make assumptions about the individual's lifestyle, but to use motivational interviewing (MI) techniques. Addressing factors such as knowledge, attitudes and beliefs can assist in targeting implementation strategies to positively affect behaviour change. One must assess the effect of gout on the quality of life, on psychosocial functioning and explore the readiness to change the risky behaviour.

- Advising about lifestyle issues, such as dietary habits, being overweight, drinking alcohol excessively and being physically inactive, pointing out that these can impact on the physical and mental health and well-being of a person. Advice can be offered about the risk of gout leading to co-morbidities which in their turn may lead to death. One should explain the benefits of lifestyle change for controlling gout and the need for long-term strategies, as well as all treatment options.

- Collaboratively write down the goals, track progress, and have continuous support to help reinforce good behaviours. Set goals and agree to achieve goals and focus on health outcomes. Ensure that the set goal will be able to be successfully attained and will be empowering and can shape behaviour (McDevitt, 2014**).** Interventions with goal-setting allow long-term health plans to be met in realistic and reachable ways; and instill long-term motivation and confidence in the ability to make lifelong changes to health.

- By supporting people to lead healthier lives, premature death can be prevented, recovery from episodes of ill health and their quality of life will be enhanced and they will be helped to make healthy lifestyle choices. The facilitator's role is to address social, medical and economic barriers which make behaviour change challenging; and to provide resources and assist in identifying and consulting with appropriate providers, emphasizing an interdisciplinary approach.

- Because behaviour change is difficult and can take time, it's important that arrangements are made for regular follow-up to keep the motivation going and to ensure that recommendations can continue. Specifying a plan for follow-up and supporting interaction will ensure better outcomes of the behaviour change exercise. It is critically important therefore, to evaluate patient perceptions of the extent to which they have received such assistance.

Client-centered activities such as listening to patients, considering their priorities, developing collaborative goals and eliciting coping suggestions that are congruent with client's values, preferences and social environment are critically imperative for the successful health outcomes.

5.3.2.1.4 Self-directed learning and chronic illness

Learning is integral to coping with chronic illness. The purpose of this sub-section is to demonstrate the role of adult learning in coping with chronic disease, including the aspect of lifestyle change. It is important to keep in mind that the difference in the way adults and children approach learning is that adults' learning is self-directional, as mentioned above under the introduction to the Knowles' andragogical learning theory. Baumgartner (2011) stated that self-directed learning is central to coping with a chronic illness. The author explained the statement by indicating that studies concerning self-directed learning and chronic illness confirmed that it can lead to transformative learning which, according to Mezirow (2009, p. 22) is "learning that transforms problematic frames of reference to make them more inclusive, discriminating, reflective, open and emotionally able to change". In addition to triggering self-directed learning, the gout condition and its co-morbidities can result in transformative learning or a change in one's worldview. Frames of reference are defined as the structures of assumptions and expectations through which we understand our experiences (Meesuaisintaa et al., 2014). It involves cognitive, affective, and conative dimensions. Individuals can also have changes in "meaning schemes" that are comprised of "specific knowledge, beliefs, value judgments, and feelings." Mezirow (2009) delineates a ten-phase transformative learning process that begins with a disorienting dilemma, such as the diagnosis of an illness, which leads to a critical assessment of one's assumptions about the world. This critical assessment leads to a new worldview that is eventually integrated into one's life.

5.3.2.2 The Chronic Disease Self-Management Programme (CDSMP)

Besides the Adult Learning Theory, the Chronic Disease Self-management Programme (CDSMP) aims to help participants build knowledge and skills for their own long-term conditions, alongside developing generic self-management skills such as problem-solving and action planning, which are particularly important for people with multiple long-term conditions. It also aims to help participants strengthen their health-related behaviours. It does this by developing health literacy, building appreciation of peer support, developing collaborative decision-making skills and building knowledge of self-management techniques as well as participants' skills and confidence to use these techniques.

Ryan & Sawin (2009) contest that while several self-management frameworks have enhanced the understanding of self-management of chronic illness, the specific processes or mechanisms of self-management have not been adequately defined, particularly from the perspective of individuals living with chronic illness.

On this note the researcher envisaged that the programme developed in this study would assist adults suffering from gout and their caregivers to comprehend the knowledge, capabilities and skills they have to fully apply them the best they can to manage their conditions.

There are as many definitions of chronic disease self-management programme (CDSMP) as there are people seeking to compile such programmes for different chronic diseases. This study is based on certain aspects of self-management theories. Developing a CDSMP implies that it is important to be knowledgeable about the disease in question and how it affects the sufferers.

The programme incorporates strategies to enhance self-efficacy and by doing so to enhance self-management behaviour and health related outcomes. The researcher is fully aware that gout is habitually accompanied by other chronic diseases and consequently a chronic disease self-management programme (CDSMP) will be fitting in this study.

Jonker et al. (2015) further state that, the underlying mechanism that explains the positive effects on health behaviour, health status, self-management behaviour and health care utilization, is assumed to be self-efficacy, defined as ‘believing in one’s capability to organize and execute the courses of action required to produce given attainments’ (Adams, 2010). The CDSMP incorporates strategies to enhance self-efficacy and by doing so to enhance self-management behaviour and health related outcomes. Three principal assumptions underlying the CDSMP have been identified as follows:

1) People with different chronic diseases have similar self-management problems and disease-related tasks.
2) People can learn to take responsibility for the day-to-day management of their diseases.
3) Confident, knowledgeable patients practicing self-management will experience improved health status and will utilize fewer health care resources.

According to Rosland et al. (2010) self-management of chronic illness does not exist in a vacuum, but rather within the context of other people and influences. Fundamental to its success are the relationships among the patients and their health care providers (primarily nurses), friends and community, and family members including the caregivers. A spectrum of patient engagement activities, including capacity building and self-management support, occur through partnerships at the individual patient and provider, community, and system levels (Bar et al., 2018).

Tucker (2013) depicts caregivers as the immediate individuals in a position to recognize changes in health status, pain level, or mood. This way they can report these changes to the health professionals who can in turn adapt the care plan to the individual's needs and communicate with the family. Caregivers can create a circle of communication between the individual living with gout, their family and health professionals to make sure a person get the best care possible.

Strom and Egede (2012) and Rosland et al. (2012) say in support that family is an important source of support for people with chronic conditions. Individuals with higher levels of family support have greater adherence to self-management and better control over their conditions.

This is particularly important in long-term self-management where family emphasis on self-reliance and personal achievement, family cohesion, and attentive responses to symptoms have been associated with better patient outcomes. In Figure 5.4 below is the Chronic Care Model (CCM) reflected.

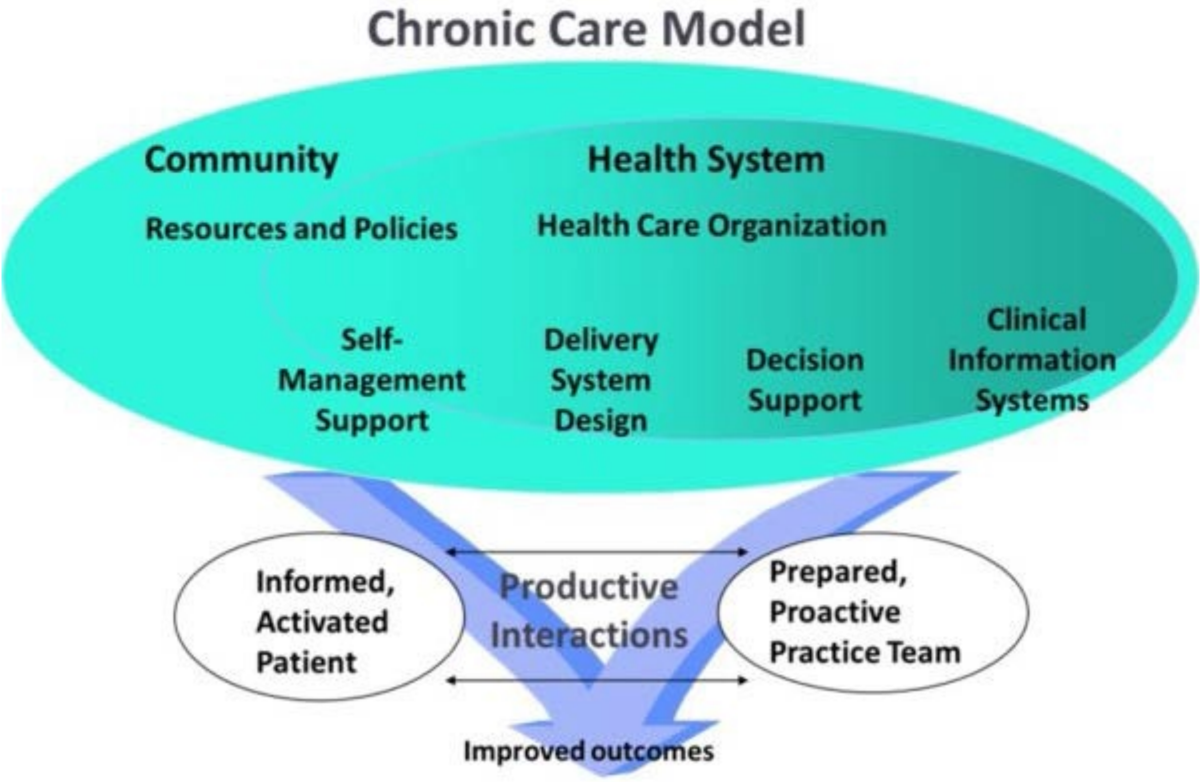


Figure 5.3: The Chronic Care Model. Adapted from Gee et al., 2015

The Chronic Care Model provides the framework for system-level improvements that will yield optimal improved patient self-care through six independent components: The community, the health system, self-management support, the design of the delivery system, decision support and clinical information systems (Gee et al., 2015).

The Chronic Care Model identifies the essential elements of a healthcare system that encourages high-quality care. The model includes evidence-based change concepts designed to foster productive interactions between informed clients, who take an active part in their care, and providers, who are prepared with resources and expertise (Reers, 2016). The CCM pursues a patient-directed approach for care and therefore points on the importance of the disease-specific knowledge of the patients. This knowledge and the activation of the patient are important factors to reach the aim of a more effective and productive cooperation between the patient and the health care provider (Gee et al., 2015).

5.3.2.3 Concluding statement in relation to programme description

In its description, the features underlying the programme are the principles of adult learning as indicated in Knowles's andragogical learning theory and the frameworks of chronic disease self-management.

The principles of adult learning underpinned the programme as was being tailored to empower adults suffering from gout and their caregivers to better manage their health challenges. Self-directed learning and chronic illness was complemented by readiness to learn as applied to behavioural change. The central concept in the management of gout is behavior change.

Behavioural support is an important part of any change attempt when navigating through the stages of behavioural change and should be recommended for all individuals who intend to engage in behaviour change. The 5 A's of assess, advise, agree, assist, and arrange comprise a manageable evidence-based behavioural intervention strategy that has the potential to improve the success of an intention for behaviour change within a homebased setting.

Self-management frameworks are known to have enhanced the understanding of self-management of chronic illness, and have shown remarkable abilities in managing symptoms that come along with suffering from gout and with caregiving. Resources such as support groups, counsellors, or friends with helpful relationships are underlying mechanism that can make effective outcomes more likely.

5.4 Outcomes of the Self-Management Capabilities

5.4.1 Programme objectives

The overall objective of this study was to develop, implement and evaluate a self-management programme with the aim to empower adults suffering from gout and their caregivers in controlling the gout condition and its concomitant diseases. These objectives form the basis for the learning content with the envisaged resultant outcomes as the self-management capabilities as presented in below:

5.4.2 The envisaged learning outcomes for the self-management programme:

- Dealing with holistic (physical and psychological) discomfort
- Client works through issues of dependency
- Creating and maintaining good interpersonal relationships
- Exploring and expressing negative feelings physically and psychologically
- Re-activating a social network

5.5 Content of the self-management programme

The learning content to be offered in the programme was based on the themes and sub-themes that had emerged during the data analysis of the study in Chapter 3 and captured in the conceptual framework in Chapter 4. At the same time, the findings were backed up by verbatim quotations of the participants' responses. The learning content for adults suffering from gout and their caregivers was presented in the format of a three-session workshop.

Outline of the content of the self-management programme focused on developing knowledge, skills and confidence on how to manage the following challenges, which, except the first one, were deduced from the study findings as follows:

- Overview of the gout condition
- Holistic (physical and psychological) discomfort
- Increased levels of dependency on others
- Loss of social relations
- Negative feelings physically and emotionally
- Social disconnectedness

The following section dealt with the teaching and learning techniques that were used during the workshop to facilitate the assimilation of the information by the participants on how to self-manage their conditions.

5.6 Facilitation techniques

Icebreakers, according to Heathfield (2018) are an activity, game, or event used to welcome and warm up the conversation among participants in a meeting, training class, team building session, or another event. Any event that requires people to comfortably interact with each other and a facilitator is an opportunity to use an icebreaker.

Lecture is one of the most ancient and reliable methods of adult instruction (Estep, 2013) and is an effective way to introduce new information to a group and to build upon learners' existing knowledge. Lecture should be applied, says Nangombe (2015) to facilitate presentations and feedback of information for about 10-15 minutes with interactive experiences, such as asking stimulating questions during class or small group discussions.

Group discussion is regarded as an ideal opportunity for group members to evaluate the logic of and the evidence for their own positions or situations (Dawson, Daniels, & Chapham, 2014). It usually involves group members with the same situations or experiences.

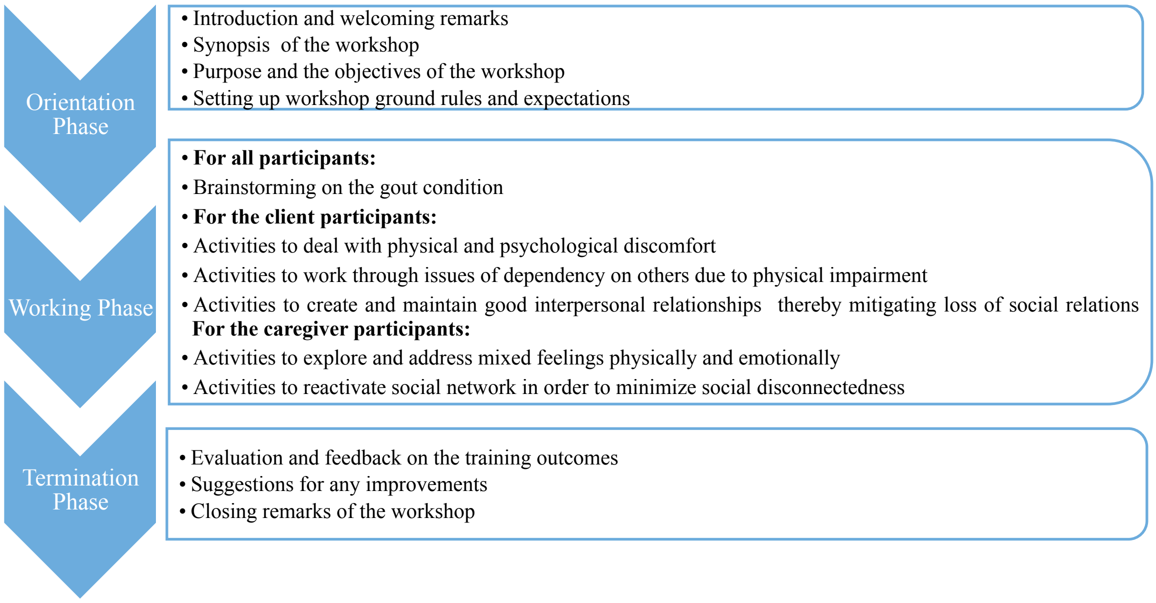
Case scenarios are based on real situations about the conditions of patients that require treatment and care, which should be presented to participants to find solutions. One of the skills to be learned during case scenarios is problem solving, critical thinking, self-directed learning and decision making (Nangombe, 2015).

Role-plays have been demonstrated as an effective learning strategy that includes an active and experiential feature that facilitates students' autonomy in their health-related learning (Chan, 2012). Problem-based learning has been widely adopted with various positive effects on students' learning, such as motivated learning, team work, problem-solving skills and critical thinking.

Plenary sessions and feedback are used to summarize topics of discussions or lessons learned in the group. This type of exercise facilitates gaining confidence during the learning process.

5.7 Guidelines for conducting training

These guidelines are used to support the facilitator to follow the three phases in the process of implementation, namely: introductory, working and termination phases. An illustration and a detailed description of the phases for the process of implementation of the self-management programme are presented below in figure 5.5.



- Introduction and welcoming remarks
- Synopsis of the workshop
- Purpose and the objectives of the workshop
- Setting up workshop ground rules and expectations

- **For all participants:**
- Brainstorming on the gout condition
- **For the client participants:**
- Activities to deal with physical and psychological discomfort
- Activities to work through issues of dependency on others due to physical impairment
- Activities to create and maintain good interpersonal relationships thereby mitigating loss of social relations **For the caregiver participants:**
- Activities to explore and address mixed feelings physically and emotionally
- Activities to reactivate social network in order to minimize social disconnectedness

- Evaluation and feedback on the training outcomes
- Suggestions for any improvements
- Closing remarks of the workshop

Figure 5.4: Guidelines for conducting training

5.7.1 Phase 1: Introductory phase

During this phase, the researcher delivered the welcoming remarks, gave a synopsis of the workshop by outlining the purpose and objectives of the training and setting up ground rules and expectations. The participants introduced themselves, and upon the researcher suggesting the if they were comfortable they were welcome to disclose the challenges they were facing with their life stories, they agreed that it would make the presentation more interesting.

5.7.2 Phase 2: Working phase

This phase enabled the facilitator to elaborate on the training content of the programme with the focus mainly on educating and training participants on how to deal with challenges that come along with suffering from gout and from caring for those suffering from this condition. The training content is outlined here:

For the adults suffering from gout:

Dealing with holistic (physical and psychological) discomfort

- Enhancing skills in monitoring and managing symptoms
- Applying pain-management techniques
- Managing emotional consequences due to chronic pain.
- Mitigating feelings of despondency
- Dealing with disrupted sleep patterns

Working through issues of dependency on others due to physical impairment

- Developing confidence and minimising dependency
- Maintaining positive outlook and hope
- Effecting moderate competent functioning

Creating and maintaining good interpersonal relationships thereby mitigating the effect from loss of social relations

- Identifying and confronting change and loss
- Modifying lifestyle to adapt to circumstances
- Re-framing expectations of life and self

For the caregiver participants:

Exploring and expressing negative feelings physically and emotionally

- Applying fatigue management principles
- Processing and sharing emotions
- Acquiring information on reducing chronic insomnia

Reactivating a social network in order to minimize social disconnectedness

- Balancing living life with caregiving
- Seeking support from family and friends

5.7.3 Termination phase

In the final phase of the training programme the facilitator needs to close off, using the following steps:

- Evaluation on the effectiveness of the training programme
- Evaluation of the entire training programme
- Suggestions for any improvement

Table 5.4: The schedule for the implementation of the programme interventions

DAY 1: 11 JUNE, 2018		
TIME	**ACTIVIES**	
08:30-09:00	Registration	
09:00-9:30	Welcoming and Prayers	
	Opening of the workshop	
	Housekeeping and Participants Introduction	
	Expectations/Ground rules	
	Volunteers energizers /Logistics	
	Aims/Purpose and Objectives of the Workshop	
	SESSIONS CONTENT	**ACTIVITIES**
09:30-10:30	**SESSION 1:** Overview of the Gout condition **Sub-objective:** To provide adults suffering from gout and their caregivers with rudimentary knowledge about gout and the basic elements of self-management.	**Activity1**:Brainstorming on: Definition causes, risk factors; Symptoms and diagnosis; Self-management elements; Concept of treatment compliance.
10:30-11:00	TEA BREAK	

11:00-12:30	**SESSION 2** Dealing with holistic (physical and psychological) discomfort **Sub-objective:** To enhance skills and knowledge in adults suffering from gout in monitoring and managing symptoms of gout, emotional consequences of chronic pain; and in dealing with disruptive sleep patterns. Open discussions on Activities 1, 2, 3 and 4	**Activity 1**: Monitoring and managing symptoms; applying pain-management techniques. **Activity 2:** Managing emotional consequences due to chronic pain. **Activity 3:** Mitigating feelings of Despondency. **Activity 4:** Dealing with disruptive sleep patterns.
12:30-14:00	LUNCH BREAK	
14:00-15:30	**SESSION 3:** Work through issues of feelings of dependency on and of being a burden to others **Sub-objective:** To equip adults suffering from gout with the skills and knowledge in developing confidence and self-efficacy, and effect positive outlook in life. Open discussions on Activities 1 and 2	**Activity 1:** Developing confidence and enhancing independency. **Activity 2:** Maintaining positive outlook thereby facilitating moderate competent functioning.

DAY 2: 12 JUNE, 2018		
09:00-09:30	Recap of day 1 **SESSION 4:** Create and maintain good interpersonal relationships thereby mitigating loss of social relations **Sub-objective:** To enhance skills and knowledge in adults suffering from gout in identifying and confronting changes and loss, in modifying lifestyle and reframing expectations of life and self. Open Discussions on Activities 1 and 2	**Activity 1:** Identifying and confronting change and loss due to the gout condition and thereby facilitate modifying lifestyle to adapt to the disease **Activity2:** Re-evaluating and reframing expectations of life and self
09:30-10:00	TEA BREAK	
10:00-11:30	**SESSION 5:** Explore and express mixed feelings physically and emotionally **Sub-objective:** To enhance knowledge and skills in caregivers with burnout in managing physical and emotional fatigue and chronic insomnia. Open Discussion on Activities1, 2 and 3	**Activity 1:** Applying fatigue management principles and minimizing physical fatigue **Activity 2:** Processing and sharing emotions **Activity 3:** Acquiring information on reducing chronic insomnia
11:30-12:30	**SESSION 6:** Reactivate social network in order to minimize social disconnectedness **Sub-objective:** To equip caregivers with knowledge and skills on balancing living life with caregiving and on seeking support from family and friends. Open Discussion on Activities 1 and 2	**Activity 1:** Balance living life with caregiving **Activity 2:** Seeking support from family and friends
12:30-13:30	LUNCH BREAK	
13:30-14:30	Conclusion	Recap of the self-management techniques

5.7.4 Summary

In this chapter, the development of a self-management programme was discussed, centered on the three approaches, namely the philosophical approach, the educational approach and the chronic disease self-management approach. Judging by the results obtained from the data analysis, it became evident that, for the adults suffering from gout and their caregivers to manage their health challenges, they needed relevant skills and knowledge to this effect.

The adults suffering from gout and their caregivers were subsequently invited to a workshop consisting of six sessions to train them on techniques to manage their health challenges as indicated below:

Session 1: Overview of the gout condition in respect to causes and risk factors; symptoms and diagnosis; self-management elements and concept of treatment compliance.
Session 2: Deal with holistic (physical and psychological) discomfort
Session 3: Work through issues of feelings of dependency on and being a burden to others due to physical impairment
Session 4: Create and maintain good interpersonal relationships thereby mitigating loss of social relations
Session 5: Explore and express negative feelings physically and emotionally
Session 6: Reactivate a social network in order to minimize social disconnectedness

In the next chapter, the implementation and evaluation of the self-management programme will be discussed.

CHAPTER 6: IMPLEMENTATION AND EVALUATION OF THE SELF-MANAGEMENT PROGRAMME

6.1 Introduction

In Chapter 5 the development of the self-management programme was specifically tailored to empower adults suffering from gout and their caregivers to take better care of themselves. The compilation of the programme content was done by taking into consideration the various health challenges that the participants are faced with. Emphasis was on maintaining healthy lifestyle behaviours, and emotional management to be undertaken by individuals in order to help direct interventions and improve health outcomes. The self-management programme was developed based on the conceptual framework for the facilitation of self-management to empower adults suffering from gout and their caregivers as well as Knowles's Adult Learning Theory as indicated on page 14.

Phase 4: Implementation and evaluation of the self-management programme

In this chapter the focus was on the implementation and evaluation of the self-management programme of the self-management techniques according to Objective 5 in Phase 4 of this study. This chapter was therefore divided into two sections; the implementation of the programme intervention (Section 1); and the evaluation of the self-management programme (Section 2) including the evaluation of the outcomes of the programme interventions.

6.2 Section 1: The Implementation Process of the Self-management Programme

This section described the procedures involved in the implementation of the intervention of the programme. Implementation is the process that turns strategies and plans into actions in order to accomplish strategic objectives and goals. The strategic plan addresses the "what and why" of activities, and the implementation addresses the "who, where, when, and how" (Olsen, 2018; Chinn & Kramer, 2015; Dickoff et al., 1968).

Purpose

The overall purpose of this study was to develop a self-management programme for adults suffering from gout and their caregivers, to better manage their health conditions that are compromised by the gout condition and the caring responsibilities.

Objectives

The objectives for this section were to:

- Facilitate the implementation of the self-management programme of the gout self-management
- Conduct supportive-educative sessions with the participants
- Equip the participants with knowledge and skills on self-management

Sample and sampling

For this phase a convenient, purposive sampling was used whereby six adults suffering from gout and five caregivers were selected to attend the workshop. The sampling was convenient as only those participants in the Metshweding village who were interviewed during Phase 1 were selected. The sampling was also purposive because the criteria used were the experiences of adults who were suffering from gout and the experiences of caregivers in their responsibility of caring, as they would be in a position to follow and participate with understanding of the presentation.

6.2.1 Preparations

The researcher and a retired professional nurse paid a courtesy visit to the participants' residence four (4) weeks beforehand to discuss with them about the envisaged workshop and who would be the facilitators; the venue of the workshop, when this would take place and the procedures were also highlighted.

For this study, a two-day workshop was designed for the implementation of a self-management programme for adults suffering from gout and their caregivers. Each participant received a programme schedule with a list of activities to be covered, a notebook and pen to record the information which they may have deemed worth noting during the presentation for future reference.

6.2.2 Schedule of the programme

The presentation of the programme was divided into three main sessions of two sub-sessions each, to be covered during a two-day workshop. The participants registered for the workshop by 08:30 in the morning. Each sub-session required at least 1-2 hours, starting from 09:00 till 10:30 for the first sub-session, the second sub-session from 11:00 till 12:30, and the last session for the day was from 14:00 till 15:30. The same pattern was followed for the second day. The time schedule provided for participants to have tea and lunch during the course of the day. Time management was crucial, as some client participants could not sit for a long time. It was also necessary to make unexpected changes to the programme schedule and to the programme activities, taking into consideration the uniqueness of the participants' learning abilities and needs and responded to them as they arose. (See Table 5.4).

6.2.3 Presentation of the programme

The success of a programme in general is closely related to “how” the information is communicated and how the integration is facilitated. The challenge was to get the participants involved in the learning experience that the workshop intended. The facilitator adhered closely to the programme schedule to make sure that all items on the programme received due attention and that all training activities were completed.

To realise the first objective, namely to facilitate the implementation of the programme, the facilitator as the agent, with the assistance of the co-facilitator, ensured that the programme was carried out within the frameworks of the philosophical approach, the adult learning approach and the chronic disease self-management approach as discussed in in Chapter 5. The first four (4) sessions concentrated on the adults suffering from gout and the last two (2) sessions focused on the caregivers. Mention is made here that the adults suffering from gout and their caregivers attended the workshop together.

Session 1: Overview of the gout condition;
Session 2: Deal with holistic (physical and psychological) discomfort;
Session 3: Work through issues of dependency on others;
Session 4: Create and maintain good interpersonal relationships;
Session 5: Explore and express negative feelings physically and emotionally;
Session 6: Reactivate social network.

6.2.4 Course Material

The training material used during the training stimulated the participation of attendees during the training sessions. The following audio visual materials were used to stimulate the participants' interest during the learning sessions: LCD for PowerPoint presentations and video show, posters and pamphlets, as well as hand-outs, an easel and blank flip charts for brainstorming.

6.2.5 The venue for the implementation of the programme

The context or the environment where this programme was implemented was at Metshweding community hall in the form of a workshop, with the view to implement it at the house hold level. The venue for the workshop was a spacious room of medium size, familiar to them, in the community hall of the village. An informal seating arrangement was adopted to put participants at ease and to contribute to the smooth running of the programme implementation. The informal seating arrangement created an environment conducive to open communication and a feeling of freedom to participate without fear and prejudice. For group work and other activities, tables and chairs were arranged in a circle. The researcher is confident that the preparation of the venue was according to SPECH of the Rural Health Education Foundation, (2009) as discussed below.

6.2.5.1 The learning environment

The environment in which training occurs is fundamentally important. Poor environments reduce the ability of participants to concentrate and "switch off" the brain, thus reducing learning. The following five elements, known as SPECH were integrated into the learning environment (Rural Health Education Foundation, 2009).

The Social Environment: Humans are social creatures and have a need to belong within a social setting. Welcome signs, introductory activities, group activities, and breaks, outside socializing opportunities were in place to facilitate interaction.

The Physical Environment: Adults need to feel comfortable to learn effectively. Hence, the comfortable conditions, the layout, room size, quality of furnishing and finishing and safety features are important physical attributes to consider for a conducive learning environment (Ahmad et al., 2015). The physical environment for adult learners must be in line with their specific characteristics and requirements in order to maximise their learning. The appearance of the venue should be attractive, with moderate room temperature, good lighting and ventilation, with minimum noise to ease learning.

The Emotional Environment: It is important to foster and maintain each person's self-esteem. Effective communication and empathy play an important role in maintaining respect and trust. The facilitator encouraged involvement, acknowledged contributions and individual differences, fostered and expected respect, maintained confidentiality, was authentic and provided constructive feedback.

The Cognitive Environment: The workshop participants need to feel that what they are learning is relevant and beneficial. Involvement and participative decision making are encouraged by describing "what's in it for them" in introducing the experience. It was important to cater for a range of participants' experience and knowledge and to provide practice opportunities and supplementary information.

The Holistic Environment: The facilitator should recognize and incorporate the range of differences and needs of each individual in each of the elements of the learning environment. Use a range of examples, use inclusive language, recognize individual and cultural differences, and provide for individual learning preferences.

6.2.6 Facilitating Adult Learning

For adult learners, learning can be defined as a relatively permanent change in behaviour or knowledge. It includes observable activity and internal processes such as thinking, attitudes and emotions (Rural Health Education Foundation, 2009). Hereunder are the factors that assisted adult people to learn more effectively during the workshop.

Multi-sense learning: A variety of techniques were used for more effective learning. The facilitator provided visual material like posters of dietary varieties, an LCD projector, lectures, group discussions, and demonstrations and roleplays. Brochures on health literacy pertaining to management of gout and its co-morbidities assisted in building knowledge and skills for their long-term conditions.

Confucius says, *"I hear, and I forget; I see, and I remember; I do, and I truly understand."* Active learning is learning by doing: Participants were to write on a piece of paper what they normally would do if they were sleepless. Others were requested to tell the class what techniques they used for pain management. A fishbowl exercise role-played breathing and meditation. This exercise was also on practice, revision and reinforcement.

Primacy and recency—remembering the first and last experiences: For every session objectives announced as to what was going to be discussed as an introduction. Again at the end of the session a summary of the presentation was given. An introduction and a summary are vitally important for learning.

Feedback between learners and the trainer: Throughout the presentation the facilitator posed questions and asked if there were any questions. Participants need feedback on their progress and facilitators need feedback on whether they are meeting participants' needs and how the session is progressing.

Meaningful material that relates to previous knowledge: The principle of adult learning was used as participants were asked to recall what they had done to manage some of the health challenges posed by suffering from gout, and for caregivers to recall what they had experienced in their caring duties.

6.2.7 An outline of the content of the workshop as presented

The second objective was to conduct supportive-educative sessions with the participants and each session was based on its specific sub-objective, with activities and outcomes (assessment) of the content matter as entailed in each presentation. Factors that assist adult people to learn more effectively according to Rural Health Education Foundation, (2009) were implemented. The outline of the content of the workshop is depicted in Table 5.4.

6.3 Section 1: Evaluation of the Self-management Programme and of the outcomes of the Programme Interventions

6.3.1 Introduction

The main purpose of evaluation of the self-management programme was to validate whether the workshop has reached its intended objective and to improve the quality of such programme should it prove otherwise (Erdoğan & Mehmet, 2016). Developing and implementing programme interventions without evaluating them will not serve any purpose, say Bugge et al. (2009). It is equally important to incorporate programme evaluation into the process to give the facilitator an understanding of how the programme works and to assess the outcomes of the programme interventions. In this study, adults suffering from gout and their caregivers, for whom the self-management programme was developed and implemented, were exposed to the content of the programme. Programme evaluation was thus geared toward the review of the effect or impact the scientific knowledge presented in the programme had on participants.

Section 2 of this chapter therefore dealt with the evaluation of the self-management programme and forms part of the fourth and last phase of the study. The self-management programme was evaluated in order to validate whether the programme interventions were likely to bring about the desired change among the participants. The process evaluation of the programme was conducted immediately after every session and at the end of the training. The programme outcomes evaluation was carried out three months after the self-management programme had been implemented to determine the changes in knowledge, attitudes and behaviour that resulted from training activities.

For the evaluation, the same researcher who facilitated during the implementation acted as the facilitator (presenter) of the programme, whilst the same retired professional nurse (the co-facilitator and also a caregiver) was writing down the comments. The methodology for sample and sampling was used according to the method under 6.2 (Sample and sampling). Since some of the participants were not able to express themselves in writing, they formed small groups and their experiences were written down by their more able colleagues.

The purpose of evaluating the programme was twofold:
Process evaluation was to assess the immediate effects in terms of knowledge on the health education activities on the adults suffering from gout and their caregivers who had received

health education messages. Outcome evaluation on the other hand was to determine improvements in participants' knowledge, skills, attitudes, intentions, or behaviours.

Objectives of evaluating the self-management programme were:

- to determine what the adults suffering from gout and their caregivers have learned during the self-management programme workshop presentation;
- to find out whether the self-management programme improved the participants' practice; and
- to identify concerns encountered by adults suffering from gout and their caregivers in the implementation of the programme.

6.3.2 Findings of the Self-management Programme

6.3.2.1 Process Evaluation

For the first objective the question was asked after the last session of the last day: *"What have you learned during the self-management programme workshop presentation?"* Some of the comments put forth by the participants on the health education messages follow here:

The acknowledgement of information gained was.....*"Some of the things, like listening to music to bring down the pain, I didn't know about them".* Yet another participant: *"I know about red meat especially beefs and that donkey meat is fine as they do not get injected ... White meat like fish and chicken were said to be safe, (.) now I am hearing that fish is also not desirable."*

One caregiver observed: *"Rearranging my sleeping environment to improve on my sleeping problem had never crossed my mind",* a statement which was supported by another caregiver who said: *"My bedroom is like wild horses went through it* "chuckling" *as I never get to tidy it up."*

In general, participants appreciated the sessions as useful, informative and educative, and felt that they had gained a lot, even laughing at the advice that the blue light of the TV has an adverse effect on their sleep—watching TV until late was habitual.

6.3.2.2 Outcomes evaluation

The outcomes evaluation examines how well a project achieved the outcomes it set out to accomplish at the beginning. It is generally a summative evaluation of the programme which can be used to make recommendations for future programme improvements. The following discussion was on how the adults suffering from gout and their caregivers experienced the self-management programme and to determine whether the programme had improved their daily living experiences.

The next step was to gather and analyse the data for evaluation.

6.3.2.3 Data gathering and analysis

The researcher made use of the six steps that are usually undertaken when conducting an evaluation of health education activities. Evaluation of the health education activities is a continuous process. Based on the feedback gained from evaluation, another plan is developed, and so the process continues. Figure 6.1 below depicts the steps in the evaluation of the health education activities.

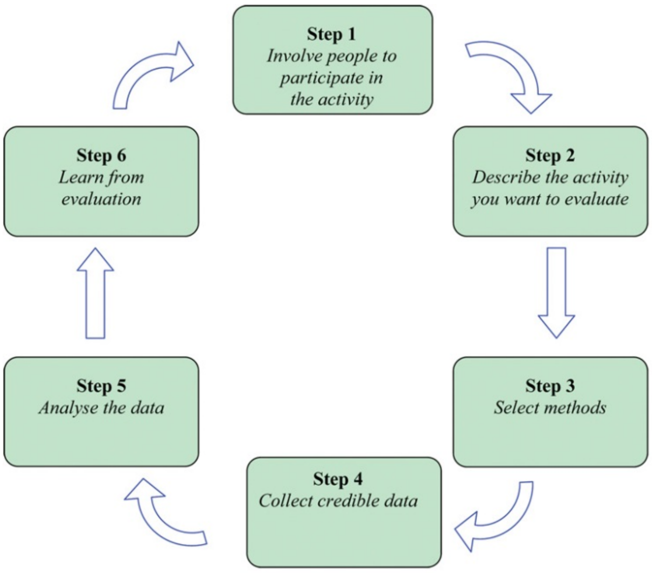


Figure 6.1: Steps in evaluation of health education activities. (Adapted from Northwest Center for Public Health Practice: University of Washington).

Six Steps of Programme Evaluation

Involve people to participate in the activities: Adults suffering from gout and their caregivers who have been taking part in the self-management programme activities were engaged. This was to ensure that all important aspects as well as their interests were addressed.

Describe the activities to be evaluated: The researcher conducted the evaluation based on the objectives and activities, as well as the content of the self-management programme. The adults suffering from gout and their caregivers were first taken in detail through the objectives and activities that were undertaken during the workshop. This enabled them and the researchers to focus on what was had been planned and what was achieved.

Select methods: Multiple data collection methods, namely focus group interviews and discussion, were conducted for the adults suffering from gout and their caregivers together, during which an audio recorder was also used, with their permission. For personal information, adults suffering from gout and their caregivers were given sheets to write on with the assistance of the co-facilitator, who was also a caregiver. The same co-facilitator also wrote on the flipchart during the evaluation sessions. Observation methods on breathing and meditation exercises were role-played.

Collect credible data: The researcher requested the client participants during the sessions if their caregivers could be interviewed privately about whether their health-related practices had changed in any way. This action was to ensure the credibility of the responses.

Analyse the data: The data from the transcript of the audio-recordings, and the field notes taken during the interviews were analysed and interpreted to give meaning to the data in order to arrive at the outcomes of the evaluation.

Learn from evaluation: Adults suffering from gout reported various noteworthy improvements such as pain management, whilst the caregivers reported diverse positive effects, the most significant of which related to improved sleep patterns.

The programme outcomes evaluation was carried out three months after the self-management programme had been implemented, at which time the programme participants commented that the programme implementation had been useful, as well as informative and educative.

The following questions dealt with Objective 2 on perceived impact of the self-management programme, with the focus on the overall impact (if any) of the self-management training in the participants' lives:

"Has the workshop had an impact on the way you manage your condition?"

"How has it changed your lifestyle in general?"

"What are some of the supports or strategies that you propose (or are necessary) to make this impact last?"

A short discussion of the analysed data of the impact of the workshop to empower adults suffering from gout and their caregivers to better take care of themselves follows:

The central theme that emerged from the workshop was that change in the lifestyle was crucial to the management of gout. Many individuals, both adults suffering from gout and their caregivers, claimed that previously they struggled to achieve reasonable control over the challenges of living with the condition and caregiving. The self-management programme had been found to improve self-efficacy, healthy behaviours, and psychological health status for adults suffering from gout and their caregivers.

The impact of the self-management programme on the way participants manage their condition:

The knowledge and benefits gained from the self-management programme were self-confidence in their ability to control their symptoms, as some would say,"… *I drink plenty of water as compared to my previous amount, although I still take some of my Clubman... And I can make and feel the difference since I started on your advice."* Some comments were on the control of some of their health problems that affected their lives, *".... I am comfortably adhering to what we were recommended to do, ... such as listening to music at our pace, doing some physical activities such as helping indoors, ... dishwashing."*

The self-management programme did help participants with controlling their emotions better, as well as improving their relationships. The following comments attest to this, *"... as soon as I realize I am about to burst out, I take several cups of breaths and then I feel calm."* Two other participants had the same experience of emotional reframing, adding that, *"...my healthy reactions had brought on healing to my relationships with my loved ones."* Another participant said*,"... I now get visitors and my children are also enjoying sticking around the house."* The ultimate solution, as some of the participants remarked is to play their part to work with their relatives and caregivers and not to be too demanding where they can do things themselves, *"...Making a cup of tea for oneself ... or getting water, showing appreciation for the favour received ... all these will make a difference."*

To show that informed individuals play an important role in reducing predisposing factors and in managing established illnesses, some of the participants had this to say, *"... Once my doctor confirmed my gout diagnosis, we worked together to come up with a treatment plan. After a lengthy discussion a plan of treatment involving both medication and lifestyle changes was made. And since then I am able to control my gout and my hypertension."*

The impacts of the self-management programme, how it has changed their lifestyle in general:

Exercise was perceived as being painful, but after the self-management programme some improvements in health status measures in mobility, pain and self-confidence were reported. *"... I have started walking around the block every morning just to test it out, see what, my pain and stiff joint have since subsided. I am doing all sorts of activities now just to be on the safe side." "....I have a huge pair of flip-flops that I wear in the house and shuffle around in the house as I cannot put on proper shoes, and they make my mobility quite comfortable and* *the pain seems to become lesser when I have moved around for a while.” “... I am a regular visitor to my nephew who is bedridden due to gout and I am always encouraging him that he will make it if he tries, my eruptive emotions are also under control.”*

Diet modification seemed to be a challenge for most of the participants, *“... As a beer drinker and kapana eater with some spice, I decided to give up on beer as it is winter, just as an excuse, now I plan to reframe my drinking habit,”* said one participant. Still another one claimed, *“... In my family, we are all are all red meat eaters since I can remember. Now all of a sudden I must eat vegetables with a little piece of meat ... It is hard as I am also not used to eating chicken.” “... Red meat and beer go together, that’s for real ... but I will have to quit one of them,”* said one participant.

One caregiver participant summarized her experience of the self-management programme reporting improvements in her psychosocial factors saying: *“The statement of balancing living life with caregiving was an eye opening for me”.* She added after a short silence, *“Resentment isn't a pretty emotion I must admit and least if you are guilt-ridden. Talking to my school friend who offered an outing with her car now and then brought some venting opportunity for me.”* Another caregiver added that *...”I feel prepared and equipped to handle a taxing situation in caring for my husband and how to reframe my emotion; through this ability I am able to improve my disrupted sleep pattern.”*

Three months after participation in the self-management programme, people continue to report greater confidence in their ability to manage their gout, less pain, and less depressed mood, anxiety, and frustration about their health.

The third objective addressed the concerns encountered by adults suffering from gout and their caregivers about the implementation of the programme. Two patterns emerged from the discussions and quotes as recommendations towards making these impacts last:

1) Time factor:

"Offer the programme on a yearly basis especially on main feasts like Christmas or Easter when the village residents are home."

"The time for conducting the workshop was not long enough."

"Make the programme a radio station programme (which could be broadcast in time slots of different languages spoken in Namibia)."

2) Implementation issues:

"Do not only invite people suffering from gout and their caregivers. Others may benefit as it looks like gout is here to stay."

"The programme is quite informative more so as we thought gout was affecting men only."

"Homes with people suffering from gout and caregivers should be visited regularly to help them with coping strategies."

"Healthcare providers need to be given the programme at the clinics to enable them to advise the patients when they come for follow-up."

This self-management programme seems to have helped people gain self-confidence in their ability to control their symptoms, and control how their health problems affect their lives. It has been evaluated by participants who seemed genuinely interested in its implementation and found it to be an effective tool to help people with chronic health conditions such as gout.

6.4 Concluding remarks

The activity provided the opportunity for the adults suffering from gout and their caregivers to understand more about their health challenges and to develop the knowledge, skills and confidence to help them manage these challenges more effectively. With the help and support of this programme and their increased knowledge, they felt more confident in helping themselves to take control of their lives and to make positive behaviour changes (Whittington Health NHS Trust, 2018).

By taking part in this self-management programme the adults suffering from gout and their caregivers were able to:

- Increase their confidence in managing their health challenges
- Improve their emotional well being
- Improve their quality of life
- Improve their communication skills
- Increase their knowledge about their health
- Improve their health challenges control.
- Meet others and share similar experiences

The self-management programme assisted the adults suffering from gout and their caregivers strengthen their health-related behaviours. It did this by developing collaborative decision-making skills and building knowledge of self-management techniques as well as their skills and confidence to use these techniques. The programme subsequently helped these participants to build knowledge and skills for their own health challenges, alongside developing generic self-management skills such as problem-solving and action planning, which are particularly important for people with multiple long-term conditions and those with challenges of caring for them (Whittington Health NHS Trust, 2014).

6.5 Summary

This chapter was about the implementation and evaluation of the self-management programme. The implementation addressed who, where, when and how of activities. The workshop was offered by the researcher and a retired professional nurse as a co-facilitator. The presentation of the programme was divided into three main sessions of two sub-sessions each, to be covered during a two-day workshop as attended by both adults suffering from gout and their caregivers. Focus was on the enhancement of self-management abilities.

The evaluation of the self-management programme was done three months after its implementation to determine its impact on the adults suffering from gout and their caregivers in terms of how they experienced the self-management programme, whether it improved their practice, and to identify concerns encountered by them about the programme and its implementation.

CHAPTER 7: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS OF THE STUDY

7.1 Introduction

In the foregoing chapter the discussion was conducted on the implementation and evaluation of the self-management programme for adults suffering from gout and their caregivers to empower them with self-management skills. The facilitation of the programme implementation was based on the principles of adult learning of Knowles' theory; the chronic conditions self-management approach was used to facilitate optimal functioning; and the philosophical theory that patients are experts in self-care was used to enhance self-confidence and self-efficacy. During the implementation phase the techniques used were lectures, discussions, demonstration and role play.

The evaluation phase provided an account of the overall perceived impact (if any) of the self-management training on the participants' lives. It is imperative when developing and implementing programmes interventions, to also evaluate such a programme (Bugge et al., 2009). The evaluation measured the outcomes of the programme interventions as was signified by adults suffering from gout and their caregivers' ability to manage their health challenges.

This chapter is a conclusion of the research study. It discusses the overview of the study, its limitations, and recommendations on the self-management programme.

7.2 Overview of Completed Study

An overview is provided of the completed study on the self-management programme. A qualitative, exploratory, and descriptive design within the phenomenological approach was used, which was contextual in nature. The study was done in phases based on the main purpose which was to explore and describe the experiences of adults suffering from gout and of their caregivers in the task of caregiving, with the aim to develop, implement and evaluate a self-management programme on self-management skills.

The research study comprised four (4) phases to achieve the objectives of the study.
The first phase consisted of two (2) objectives of conducting situational analysis.

7.2.1 Phase I: Situational analysis

Objective 1: To explore and describe the experiences of adults of suffering from gout

Objective 2: To explore and describe the experiences of caregivers in taking care of adults suffering from gout.

7.2.1.1 Conclusion

In phase one the situational analysis was done through the fieldwork and by conducting interviews with adults suffering from gout and their caregivers. The data obtained were analyzed and categorized upon which key themes and sub-themes were derived. These themes were utilized as the "backbone" of the framework for the intended programme.

For objective 1 of Phase 1, in-depth individual interviews were conducted with fourteen (14) adults suffering from gout in the Omaheke region to explore and describe their experiences of suffering from gout. It emerged from the findings that adults suffering from gout experienced physical and psychological discomfort, increased levels of dependency on others due to physical impairment, and loss of social relations.

The key theme (theme 1) of Objective 1 entailed story telling of experiences of physical and psychological discomfort. Pain seemed to be the central experience of gout. For many participants, the first and most unpleasant and distressing experience was excruciating pain. Unrelenting pain causes a great deal of mental and physical suffering. When physical pain is a problem, holistic pain relief supplements and techniques can ease discomfort, make movement easier, and provide emotional health benefits. From the perspective of holistic healing, Silver (2009-2018) suggests that it is important to address the physical causes and symptoms of pain as well as the emotional aspects that accompany them. Pain interferes with sleep and adds to stress, and as quality of life diminishes, the tendency to cut back on enjoyable activities and social interactions was also a dominant concern.

The key theme (theme 2) of Objective 1 pointed to increased levels of dependency on others due to physical impairment. The corresponding sub-themes included reduced self-efficacy and low self-confidence which many psychologists postulate that they have the power to limit an individual in all areas of life resulting in dependency. The sense of dependency and being a burden to others derive from patients' dependence on others for help with every aspect of their daily living or of receiving care from someone else. Feelings of despondency and of being a burden to others result from the realization that the individual is unable to effect moderate competent functioning, and it came out as a strong theme.

The key theme 3 (theme 3) is related to loss of social relations. A number of sub-themes transpired such as isolation due to immobility, appearance and pain unpredictability. Lifestyle changes and adjustments translated into following a specialized diet, needing exercise to reduce medical symptoms, and role changes as breadwinner and parent.

Objective 2 of Phase 1 focused on caregivers’ experiences of caring for adults suffering from gout. Focus group discussion was conducted with seven (7) caregivers. The findings revealed that caregivers experienced mixed feelings, physically and emotionally, and social disconnectedness in taking care of adults suffering from gout.

The key theme (theme 1) of Objective 2 indicated that caregivers were experiencing mixed feelings physically and emotionally. The emerging sub-themes were physical fatigue with feelings of a lack of physical and mental energy. This interfered with the performance of usual and desired daily activities. Emotional exhaustion came from guilt that one is not doing enough for the care recipient while also experiencing resentment for not getting enough help. Burn-out was tied to increased instances of chronic insomnia leading to shortness of temper.

The key theme 2 (theme 2) concerned social disconnectedness, and one sub-theme was the limitation of the social network, which leads to lower life satisfaction. Because caregivers don’t have the time they need, many have dropped out of any outside activities. There was also lack of social support in caring for the care-recipient who at times resented needing someone else to attend to them.

The study also included the second phase, namely the construction of the conceptual framework.

7.2.2 Phase 2: Conceptual framework

Objective 3: To formulate the conceptual framework

7.2.2.1 Conclusion

In phase two the conceptual framework was derived from the results of Phase 1, which was used to guide the development of a self-management programme to empower adults suffering from gout and their caregivers in self-management skills. Three essential ingredients of a conceptual framework, according to Dickoff et al. (1968) were identified: the goal content specified as the aim of the activity, the prescription of the activity for goal realization, and a survey list that accompanies the presentation of the prescription for the activity in terms of the goal realization. The self-management programme included the activities suggested in the survey list of Dickoff et al. (1968) namely, agents (facilitators), recipients (clients and caregivers), context (homes of the clients), dynamics (challenges experienced by clients and caregivers in the context of managing health-related symptoms), procedures (intervention to mitigate these challenges), and terminus (clients and caregivers' abilities to manage the challenges). On completion of the construction of the conceptual framework the programme development followed.

7.2.3 Phase 3: Programme Development

Objective 4: To develop the self-management programme

7.2.3.1 Conclusion

Phase 3 dealt with the development of the programme for adults suffering from gout and their caregivers. The researcher utilized the data analysis conducted in Phase 1 and the survey list of Dickoff et al. (1968) in Phase 2. The content for the programme was supplemented with the views of the adult learning theory by Knowles. Additional information was adopted from Chronic Conditions Self-management Programme of the Self-Management Resource Center (2018), a programme highly interactive, focusing on building skills, sharing experiences, and support. Phase 4 dealt with the implementation and evaluation of the self-management programme. In addition, the philosophical theory of self-care further strengthened the content of the programme.

7.2.4 Phase 4 – Programme Implementation and Evaluation

Objective 5: To implement (Section 1) and evaluate (Section 2) the self-management programme.

7.2.4.1 Conclusion

Phase 4 involved the implementation and evaluation of the self-management programme that introduced interventions for self-management at home. The researcher incorporated the concepts of adult learning by Knowles and The Chronic Disease Self-management Programme (CDSMP), which aimed at developing self-management skills such as problem-solving and action planning, as they are particularly important for people with multiple long-term conditions; and the philosophical notion that patient expertise in self-care is a cornerstone of disease management (Lohman, 2016; Pickard & Rogers, 2012).

The self-management programme implementation was performed over a period of two 2 days in the form of a workshop. The programme consisted of six sessions, the first four focusing on the self-management skills of the clients, and the last two dealing with the caregivers' self-management skills. The discussion was on the key themes with their sub-themes and comprised the following learning content:

Session 1: Overview of the general knowledge about the gout

Session 2: Dealing with physical and psychological discomfort

Session 3: Working through issues of dependency and feelings of being a burden to others

Session 4: Creating and maintaining good interpersonal relationships, thereby mitigating loss of social relations

Session 5: Exploring and expressing mixed feelings physically and emotionally

Session 6: Reactivating a social network in order to minimize social disconnectedness

The self-management programme covered topics such as: techniques to deal with problems associated with suffering from gout such as dealing with physical and psychological discomfort, modifying lifestyle—including healthy eating, appropriate exercise and appropriate use of medications, and communicating effectively with family, friends, and health professionals or caregivers. On the other hand, techniques to deal with problems associated with caregiving challenges such as how to mitigate negative emotions and to reconnect lost relationships were addressed.

Throughout the six sessions, the facilitators assisted participants in developing a range of skills to support self-management. These included tips on how to adopt healthier lifestyle behaviors, strategies for effective interactions between clients and caregivers and with healthcare providers and family members, and instructions on how to use medications correctly. Each session focused on a different core skill.

Evaluations were conducted after each session of the presentation and again on activities of the day. The overall evaluation of the workshop was done on the last day. The programme outcomes evaluation was conducted three months after the implementation of the programme on the basis of a once-off focus group discussion for the adults suffering from gout and their caregivers. They reported better control over the challenges of living with the condition and of caregiving, and self-confidence in their ability to control their symptoms.

7.3 Limitations

Using the phenomenology approach in this study poses some limitations observed during focus group discussions where participants were inclined to concur with their co-participants, making the findings look uniform.

For some client participants interviews were done in their residence, which was an ideal environment though. Consequently, there were always disturbances such as interruptions and movement outside. This could have led to lost valuable information as at time participants would forget what they wanted to say due to disturbance in the flow of the discussion. These interruptions could also influence confidentiality.

Self-reported behaviour change during the programme evaluation had to be verified by caregivers, an action which might have affected the client participants' feelings of not being trustworthy.

The client participants could have benefitted more from the programme had it included more and longer sessions to keep the self-management attitude under attention, which was not feasible given the limiting effects of their condition. Additionally, time and financial constraints were the blocking concerns.

Due to time and cost, it was neither viable, nor feasible to include other constituencies. This study looked at twenty-one (21) participants, the majority of whom were located in the northern part of Omaheke region within three constituencies. It is therefore a limitation, in that qualitative research findings are not intended to be generalized directly to populations.

7.4 Recommendations

The findings of this study yielded a number of recommendations with an emphasis on empowering adults suffering from gout and their caregivers to enhance their self-management skills. Gout has increased in prevalence over the last few decades, making it the most common inflammatory arthritis. The rising burden thereof is evidence for a significant prompt to optimize treatment and management including patient education, diet and life style changes, at individual, community and national levels. Meeting their needs through programme adjustments and continued research will benefit all of the stakeholders involved.

Education

The programme could be integrated into the teaching institutions' curriculum to endow the students with the knowledge of diagnosing and treating patients with gout at the primary health care facilities.

Promotion of self-management through education fits appropriately into the overall healthcare quality picture. Therefore, it is important for self-management education interventions to be fully integrated into primary and secondary healthcare systems, to make education available to every chronic disease patient.

The programme could be used as a teaching resource and reading material for healthcare professionals to improve the execution of their daily encounters with patients. Healthcare providers need to be given the programme at the clinics to enable them to advise the patients when they come for follow-up. For this purpose, the Ministry of Health and Social Services might develop a brochure for gout management to be placed at the various health facilities.

The programme could be made a yearly event especially on main feasts like Christmas or Easter when the village residents are home, or be slotted in social media e.g. radio station programme (which could be broadcasted in time slots of different languages spoken in Namibia), for accessibility by the intended audience, even for preventative purposes.

Practice

There are several recommendations for practice based on the research findings that can influence patients, caregivers and healthcare education surrounding management of the gout condition challenges and also as they affect the caregivers' overall health.

The Chronic Disease Self-Management Programme interventions are proven models of successful self-management programmes and have been adopted by healthcare systems in overseas countries such as the United States, New Zealand, the United Kingdom and elsewhere, and have been translated into numerous languages for use around the world. In the Namibian context with a varied multilinguistic population, following the examples mentioned above, would address the patient-caregivers-healthcare professional interactions.

These interventions of models could also be used as a cross reference in support of the newly developed chronic disease self-management programme of this study, to complement and support its interventions.

The healthcare system should embark on offering tailored community-based self-management intervention programmes for people living with chronic conditions such as gout, for improved health outcomes in the targeted population.

Homes with people suffering from gout and caregivers should be identified and visited regularly to enquire about new health challenges encountered and to help them with coping strategies.

As many gout sufferers would stop treatment after they stopped experiencing symptoms, it is important to encourage medication compliance so that they may experience long-term benefits. A broader approach, including interactions with the health system to link participants with local self-management resources such as linking with an exercise class, may have greater impact.

It is therefore recommend that integration of the ingredients of the programme be integrated into the daily healthcare practice of health professionals working with adults suffering from gout. This may be achieved when health professional guidance starts from people's possibilities, considering their physical or cognitive limitations, stimulating them to focus on their own attainable goals and providing them with the experience of being successful.

Future Research

This study revealed some areas of potential research that can add to the body of knowledge concerning the phenomenon of adult learning in the area of gout management. Future research should focus on a larger and more ethnically diverse group of lower incomes and education levels.

Additional further research on the influence of the media and communication is needed to determine if it will offer insight on the risk factors, management, and treatment compliance, particularly for adults without any tertiary education, and to help public health institutions and healthcare professionals develop better self-management programmes for individuals suffering from gout.

7.5 Contribution to the body of Knowledge

The findings of this study were based on the themes after the data was analyzed and the results interpreted. New matters relevant to adults suffering from gout and their caregivers were thus revealed. A new understanding of existing issues regarding suffering from gout and concerning caring for adults suffering from gout has brought to the fore a new body of knowledge about the experiences of these two groups. These experiences contributed to the development of a conceptual framework using a reasoning map based on the survey list described by Dickoff et al. (1968). Subsequently, the data about their experiences was incorporated in the self-management programme that was developed.

Whilst the practice for care given to an individual at home was left in the hands of caregivers who might be family members or others, the literature review revealed information about paid caregivers who could collectively be supported by family members or a local organization. By this agreement the burden from the traditional caregivers could be substantially lightened. The literature review also revealed information about certain schemes termed “homecare re-ablement” in the UK, and “restorative home care” in the USA, New Zealand and Australia. These schemes aim to provide time-limited intensive input to facilitate users’ confidence and ability to carry out their own care independently, thereby reducing the need for ongoing homecare services. The Ministry of Health and Social Services could introduce these services for the same benefits.

7.6 Chapter Summary

This chapter was a final exposition which discussed the overview of the study, its limitations, and recommendations regarding the research possibilities on education and practice. It also looked at future research that could add to the body of knowledge. It then ended with the overall concluding remarks.

7.7 Concluding Remarks

People suffering from gout as a chronic condition are their own principle caregivers, living with the illness 24 hours a day. Experience shows though that caregivers are indispensable partners during this 24 hour shift, acting as facilitators who are also physically and emotionally affected during the caregiving. Therefore significant and healthy human relationships are successful only when they are reciprocal and mutual. The care recipient may need a great deal of assistance, but the needs of the caregiver must also be met in order for the relationship to remain healthy.

This study and the implementation of the self-management programme gave the participants the knowledge and tools needed to empower them to better manage their condition of ill health and the concomitant challenges. The concluding remarks were that the self-management programme would help adults suffering from gout and their caregivers to control their symptoms, better manage their health problems, and lead fuller lives.

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Addendum 1

Self-management skills

Gout is one of the most painful rheumatic diseases, and results from uric acid that accumulates in the joint space between two bones. It causes swelling, redness, heat, pain, and stiffness in the joints.

There are certain things that can lead to you getting gout such as medicines - aspirin that increases uric acid levels and foods like meat, fish and seafood. Alcoholic drinks also promote the production of uric acid, and can reduce the effects of gout drugs. Sugary drinks like cola as well as fruit juices can also increase the risk of gout. Obesity increases the risk of getting gout because of the extra pressure put on joints and changes to body make-up that are caused by excess fat.

Activity 1: Practicing self-management skills

- To help prevent future attacks, take the medicines as prescribed.
- Carefully follow instructions about how much medicine to take and when to take it.
- Tell the doctor about all the medicines and vitamins taken to decide if any of them increase the risk of hyperuricaemia.
- Plan follow-up visits to evaluate progress.
- Maintain a healthy, balanced diet; avoid foods that are high in purines;
- Drink plenty of fluids, especially water. Fluids help remove uric acid from the body.
- Exercise regularly and maintain a healthy body weight.
- Lose weight if overweight, but do not go on diets designed for quick or extreme loss of weight because they increase uric acid levels in the blood.

Assessment: Self-management activities to lower the gout attacks

What have you learned about:

Self-management skills?

Which activity/ies have you adhered to?

Which activity/ies worked out for you?

Which activity/ies did not work out for you?

Addendum 2

Holistic discomfort (physical and psychological)

Patients with high levels of chronic pain experience depressive mood, confusion, fatigue, problems with sleep, anxiety and anger, low vigour, and poor self-efficacy. The more anxious and stressed people are, the more tense and constricted their muscles are, over time causing the muscles to become fatigued and inefficient.

Activity 2: Monitoring and managing symptoms

- Monitor symptoms through regular blood tests around once a month to check that uric acid levels are low enough to prevent attacks and long-term problems.
- Blood tests every one or two years for the uric acid levels and to check kidney function. If high the uric acid levels damages the kidneys.
- People with gout often have high blood pressure, high cholesterol, kidney problems, and diabetes or heart problems. Look for these conditions so that they can be treated as necessary
- Pain-management techniques of the cold and heat application penetrate deeper into the muscle and tissue. One can use a warm water bag or any bottle with warm water and place it on the affected area.
- The exercise promotes the physical activity and interrupts the vicious cycle of pain. It also reduces mobility found in some chronic conditions such as gout. These exercises include walking, swimming, horse riding or cycling. Massaging is using the same principles as it eases pain by working tension out of muscles and joints, relieving stress and anxiety.
- The mind-body techniques of meditation is emptying of the mind of thoughts, or the concentration of the mind on one thing, in order to help the mental or spiritual

development, contemplation, or relaxation. It takes the concentration off the pain as does listening to any kind of music which can distract a person from pain or discomfort.

- Breathing exercises helps in restoring a sense of control over the body, and makes one feel most calm and relaxed

Assessment: Skills in monitoring and managing symptoms of gout

What have you learned about:

Monitoring and managing symptoms of gout?

Which skills have you used?

Which skills worked out for you?

Which skills did not work out for you?

Activity 3: Managing emotional consequences of suffering from chronic pain

- Practice emotional venting by expressing how you feel because emotional suppression can lead to anger, sleeplessness, anxiety and depression and other negative emotions.

- Lifestyle changes can help lift depression faster, and prevent it from coming back. These include:

- Regular exercise can be as effective at treating depression as medication. It acts as feel-good brain chemicals, and triggers the growth of new brain cells and connections, just like antidepressants do. Even a half-hour daily walk can make a big difference in the way you feel. For maximum results, aim for 30 to 60 minutes of aerobic activity on most days.

- Strong social networks reduce isolation, a key risk factor for depression. The more you cultivate your social connections, the more protected you are from depression. Keep in regular contact with friends and family, talk to trusted family members or friends, or consider seeking out new connections at a depression support group,

- Eating well is important for both your physical and mental health. A well-balanced diet has always been medication for a lot of ill-health conditions. Eating small, well-balanced meals throughout the day will help you keep your energy up and minimize mood swings. Anxiety and depression often trigger cravings for carbs which may subsequently trigger the gout flare (Chowdhury, 2017).

- Too much stress exacerbates depression and puts you at risk for future depression. Take the aspects of your life that stress you out, such as work overload or unsupportive relationships, and find ways to minimize their impact. Exercise will boost your mood for body and mind.

- Aim for somewhere between seven to nine hours each night of sleep. Sleep has a strong effect on mood. When you don't get enough sleep, your depression symptoms will be worse. Sleep deprivation exacerbates irritability, moodiness, sadness, and fatigue.

Assessment: Skills in managing emotional consequences of suffering from chronic pain
What have you learned about:

Managing emotional consequences?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Activity 4: Maintaining positive outlook in order to reduce feelings of despondency

- Savour pleasure: Feeling and appreciating pleasurable experience as it unfolds, whether a meal, an outing or a planned visit with a friend will give you a sense of wellbeing physically and mentally.

- Practice gratitude: Gratitude is a thankful appreciation for what one receives, whether tangible or intangible.

- Cultivate mindfulness: Mindfulness is focusing attention on the present moment, in both pleasant and unpleasant experiences, and not get caught up in worries about the future or regrets over the past. This exercise enables one to form deep connections with others.

- Retain a sense of purpose: It is to keep your life as normal as possible even in trying moments, considering others and to focusing on what one can control.

- Emphasize the positive. Winnowing out and focusing on the positive aspects of a situation are key factors in acquiring resilience—the ability to bounce back from bad times—that will help you weather the losses.

Assessment: Techniques in mitigating feelings of despondency

What have you learned about:

Techniques to maintain positive outlook?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Activity 5: Dealing with disruptive sleep pattern.

The presentation had a bearing on both the client and caregiver participant as both groups shared the same problem of sleep disorders.

- Controlling exposure to light: Be exposed to bright light and blue light during the day. Limit exposure to blue light from TV and computer screens at night. Avoid bright lights because even the light from your alarm clock can be disruptive - turn it away from you.

- Adding more structure to the day: Schedule social interaction, get regular exercise, and other activities. These will improve the physical readiness for the coming sleep.

- Rearranging the sleep environment: Keep your bedroom clear of clutter. This might be a good project for you and the person you're caring for. Make the sleep environment as inviting and comfortable as possible; minimize the amount of noise in the sleep environment. Find your ideal sleep atmosphere which is cool, dark, and quiet.

- Maintaining regular sleep-wake times: The brain clock needs to adjust to the sleep pattern that you adhere to, with the bedtime and wake up time. Napping too close to bedtime will interfere with night sleep time, therefore cultivate short naps early in the day to improve overall restfulness.

- Avoid stimulants: These include such as caffeine, nicotine, and alcohol especially in the evening. It may take you a while to eliminate these stimulants, but ultimately your health and your sleep will benefit.

Assessment: Techniques in dealing with disruptive sleep pattern

What have you learned about:

Techniques to deal with disruptive sleep pattern and/or chronic insomnia?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Addendum 3

Dependency on others due to physical impairment

The physical capacity to move, coordinate actions, or perform physical activities is significantly limited, impaired, or delayed and is exhibited by difficulties in one or more of the following areas: physical and motor tasks; independent movement; performing basic life functions. Other self-care tasks require more complex thinking skills, such as managing finances, or transportation, shopping and meal preparation housecleaning and home maintenance, managing communication, and managing medications.

Accordingly, such a person becomes dependent on others for assistance. This calls for a need to master certain skills that promote independence, and mastering a skill calls for self-confidence. Low self-confidence and low self-efficacy have the power to limit an individual in all areas of life. They can facilitate dependency, prevent an individual from having healthy relationships, and even keep one disconnected from one's inner power (Chowdhury, 2017).

Activity 5: Developing confidence and self-efficacy thereby enhancing independency

- Look at what you've already achieved: It is easy to lose confidence if you believe you haven't achieved anything. Make a list of all the things you're proud of in your life, whether it's winning a horse race or learning to surf. Keep the list close by and add to it whenever you do something you are proud of. When you're low in confidence, pull out the list and use it to remind yourself of all the awesome stuff you have done.

- Think of things you're good at: Everyone has strengths and talents. Recognizing what you're good at, and trying to build on those things, will help you to build confidence in your own abilities. Exercise is a mood-booster for body and mind to help one feel good raises self-esteem and confidence and can improve relationships.

- Set some goals: Set some goals and set out the steps you need to take to achieve them. They can be things like baking a cake or planning a night out with friends. Just aim for some small achievements that you can tick off a list to help you gain confidence in your ability to get stuff done.

- Talk yourself up: You are never going to feel confident if you have negative commentary running through your mind telling you that you are no good. Think about your self-talk and how that might be affecting your self-confidence. Treat yourself like you would your best friend and cheer yourself on.
- Get a hobby: Try to find something that you are really passionate about. When you have worked out your passion, commit yourself to giving it a go. Chances are, if you are interested or passionate about a certain activity, you are more likely to be motivated and you will build skills more quickly.

- Be philanthropic - Create a strategy about how you want to express your appreciation. Being altruistic concerns regard for other's feelings and behavior that show a desire to help other people and a lack of selfishness. (Merriam-Webster).

- The sharing of household chores can lead to greater independence and also reduces the burden on others in the household. During the gout flares free times, make use of the opportunities to help with activities which you are capable of.

Assessment: Skills in developing confidence and self-efficacy

What have you learned about:
Techniques in developing confidence and self-efficacy?
Which techniques have you used?
Which techniques worked out for you?
Which techniques did not work out for you?

Addendum 4

Good interpersonal relationships

The experiences of chronic pain have a dramatic impact on recovery, largely because of their effect on social isolation and reintegration. Gout rarely improves one's social life. Part of this is logistics - movement may be difficult and not every place is handicap accessible. But part of it is psychological: Gout sufferers become self-conscious because of a wheelchair or walker or some other deficit. They often feel diminished by the deficits they are left with, and seek safety and familiarity to avoid humiliation and ridicule. The experience of losing something we value is a part of life no one can escape from. When a feeling of loss happens, learning to cope is essential to be able to bounce back.

Activity 7: Identify and confront change and loss thereby facilitating lifestyle modification.

- Acknowledge and accept the feelings: The first step is to learn to bring the feelings out by expressing how you feel of loss by discussing with a friend, a confidante, or even going to a psychiatrist.

- Start taking steps to fill up the void within: When you lose something of value to you, there is usually an empty spot within you that craves your attention. Feel liberated and move forward, focus on modifying your relationship with it. You can do this by changing your relationship from an attachment to a detached way of connection.

- Replace the negative feelings with positive ones: Cognitive modification is a great tool to be used here thereby learning to grow from the loss. Use statements that focus on looking at the loss as something temporary.

- Learn to become more emotionally stable: Emotional health is important to be able to go through life's ups and downs. People with high emotional intelligence learn to feel more positive emotions and less negative ones even when life's challenges hit them. They learn to regulate their emotions and become more resilient.

- Start evaluating your faith: People with a set of value system that brings about a sense of reassurance and trust in life and in something bigger than themselves can bounce back easier from a sad situation

Assessment: Identify and confront change and loss due to the gout condition

What have you learned about:

The techniques to identify and confront change and loss?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Activity 8: Re-evaluating and reframing expectations of life and self

- Take time to be alone daily - Just think, read a journal, pray, meditate and you will be able to quiet your mind and increase your sense of balance, joy and inner peace. This will facilitate learning more about yourself without judgment. Make yourself a priority.

- Uncover your core values - Re-examine and identify your core values. Once you figure out what you really want today, then you'll want to align what you do every day with your top values. Through this you will be able to picture what you want, picture yourself feeling confident in a new situation or progressing in rehabilitation.

- Change your negative self-talk - Begin listening to what you say about yourself and then talk back to negative self-talk with the truth. Affirm yourself every day. Negative, critical, hurting comments need to change.

- Relinquish expectations - Avoid setting expectations for yourself because then you block yourself from being your true self in the current situation. Take some time to examine your expectations, and then let them go. Letting go of expectations helps you know yourself and just be yourself in all sorts of situations, whether you are giving your full focus to a project or a conversation.

- Relinquish conditional relationships - Avoid living up to someone's expectations of yourself or how you should behave in a relationship. It becomes hard to know what we really want, especially when those expectations feel oppressive to us. Others' expectations can overshadow and blur our true selves.

- Nurture yourself - Practice self-care physically, emotionally, mentally and spiritually. Once you choose to nurture yourself, you are on your way to inner fitness, greater self-awareness and higher self-esteem. Doing what makes you feel good and most relaxed will help you connect with your true self. This can include everything from taking a yoga class to reading a great book to going to bed early. It's so much easier to get to know your best self when you're feeling rested and relaxed.

Assessment: Re-evaluating and reframing expectations of life and self

What have you learned about:

Techniques to re-evaluate and reframe expectations of life and self?
Which techniques have you used?
Which techniques worked out for you?
Which techniques did not work out for you?

Addendum 5

Explore and express mixed feelings physically and emotionally

Stress and work life balance are often at odds with each other. Caregiving activities are interfering not only with one's mental, physical, and emotional health, but also with other formal commitments outside of the home, or relationships with friends and family. As a productive individual who has other formal commitments, caregiving for an individual while trying to engage in them can be exhausting (Elizz, 2016). People seem deeply confused about the nature of negative emotions and how to process them, says Henriques (2017). There is a need in teaching caregivers how to understand their emotions and how to adaptively relate to and process them.

Activity 9: Applying fatigue management principles and minimizing physical fatigue

- Energy conservation: Practice this by maximizing the quality and quantity of activities while minimizing energy expenditure in performing these activities.

- Pace yourself, and rest before fatigue causes worsening of symptoms. During your daily chores, avoid stress and overworking.

- Modification of activities: Reduce time spent on fatigue-inducing activities; alter the sequence of certain sets of activities and inserting rest periods between activities.

- Modification of the environment: Keep the environment cool, ventilated and well-lit. This will reduce the feeling of being fatigued.

- Physical Exercises: Engage in individual and/or group exercise programmes (e.g., swimming, individualized exercises, aerobic exercises, or special types of exercises such as yoga) (Chan. n.d.)

Assessment: Applying fatigue management principles to minimize physical fatigue

What have you learned about:

Fatigue management principles?

Which principles have you used?

Which principles worked out for you?

Which principles did not work out for you?

Activity 10: Processing and sharing emotions

- Shift the attention somewhere else, from the immediate surroundings and their complexity and direct it internally. Taking some time there, inside and taking care of and listening to the self, everything will balance again.

- Think about the near future, about tomorrow, or coming week; the present is completely occupied by fear, stress, and frustration. Every time a worry appears in the mind, put it off for later when calm and relaxed. Then, at that time one can reflect on and find solutions for the problems.

- Find escape route of self-expression such as writing, drawing, or painting which may act as processing the emotions. Communicating the circumstances, thoughts, and feelings surrounding emotional event one can exercise more control over their emotions and relationships if they take the time to develop self-awareness and communication competence.

- Go running, keep silence or use nature, get a coffee with friends, reading books, listening to music, or finding a precious moment alone.

- Meditation can help with dealing with intrusive thoughts, reduce stress, improve your attention, and help with daily anxiety. People could seek out happy situations and communicate positive emotions even when they do not necessarily feel positive emotions (Kotchemidova, 2010).

Assessment: Processing and sharing emotions

What have you learned about:

Techniques to process and share emotions?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Addendum 6

Reactivate social network in order to minimize social disconnectedness

The "loss of self" is frequently mentioned by caregivers who report no opportunities to engage in the activities they value most. A person's activities and social connections in daily life seem to be highly related to his or her feelings of identity and maintaining an acceptable sense of identity is essential to wellbeing. The most important thing is for caregivers to not become isolated as they take on more responsibility and as social life moves into the background. It is important also to start taking care of yourself as a caregiver, changing some things about how you care for yourself and/or getting some support for you.

Activity 11: Balance living life with caregiving

- Believe in social sustenance: Believe and be willing to test out that it will help sustain you
- by renewing your morale and energies. Seek re-engagement with important relations, make new friends, or join support groups. This will come about when you embrace the idea that seeing friends makes you hardier, then you no longer will suffer guilt over having fun.

- Fiercely protect your slotted social time: Schedule social time on at least a weekly basis that you won't cancel for anything less than a full-blown emergency. Go for lunch, a walk in the park or a chat over coffee. You will gain a greater sense of control over your own lives that prevents feelings of helplessness and depression.

- Choose understanding companions: Seek out those who understand the caregiving impulse and mission. In similar circumstances meet at support groups, at hospitals and churches or online groups.

- Seek the opportunity to share your fears, guilt, and sadness, as well as your successes. These people are your peers and can be your sounding board as well as your champions. Such activities provide comparable amounts of emotional uplift.

- Occasional phone calls, emails and texts with other family members can bring lightness. Humorous exchanges can even have the salutary effects of a mini-respite.

Assessment: Balance living life with caregiving

What have you learned about:

Techniques to balance living life with caregiving?

Which techniques have you used?

Which techniques worked out for you?

Which techniques did not work out for you?

Activity 12: Seek support from family, friends, local organizations

- Talk to someone you trust like a doctor, family member, friend or local non-profits organizations who have experience if you think that you’re experiencing caregiver burnout and get additional help for the person you are caring for.

- Consider inviting family and close friends: During this meeting say what you need, plan for care and ask others for assistance; this may help relieve anxiety and better prepare for the future. If possible, it's helpful to include the care recipient in this meeting.

- Occasionally pay a visit to a health provider: You as caregivers are truly at risk of physical and emotional problems of your own as often you become so immersed in your role that you are unable to see your own health decline right before your eyes.

- Take advantage of community resources: Learning about the gout diagnosis could increase knowledge and confidence’ and may help to understand the disease process and plan ahead realistically.

- Encourage re-engagement with important relations, make new friends, or join support groups.

Assessment: Seeking support from family, friends, local organizations

What have you learned about:

Seeking support from family, friends, local organizations?

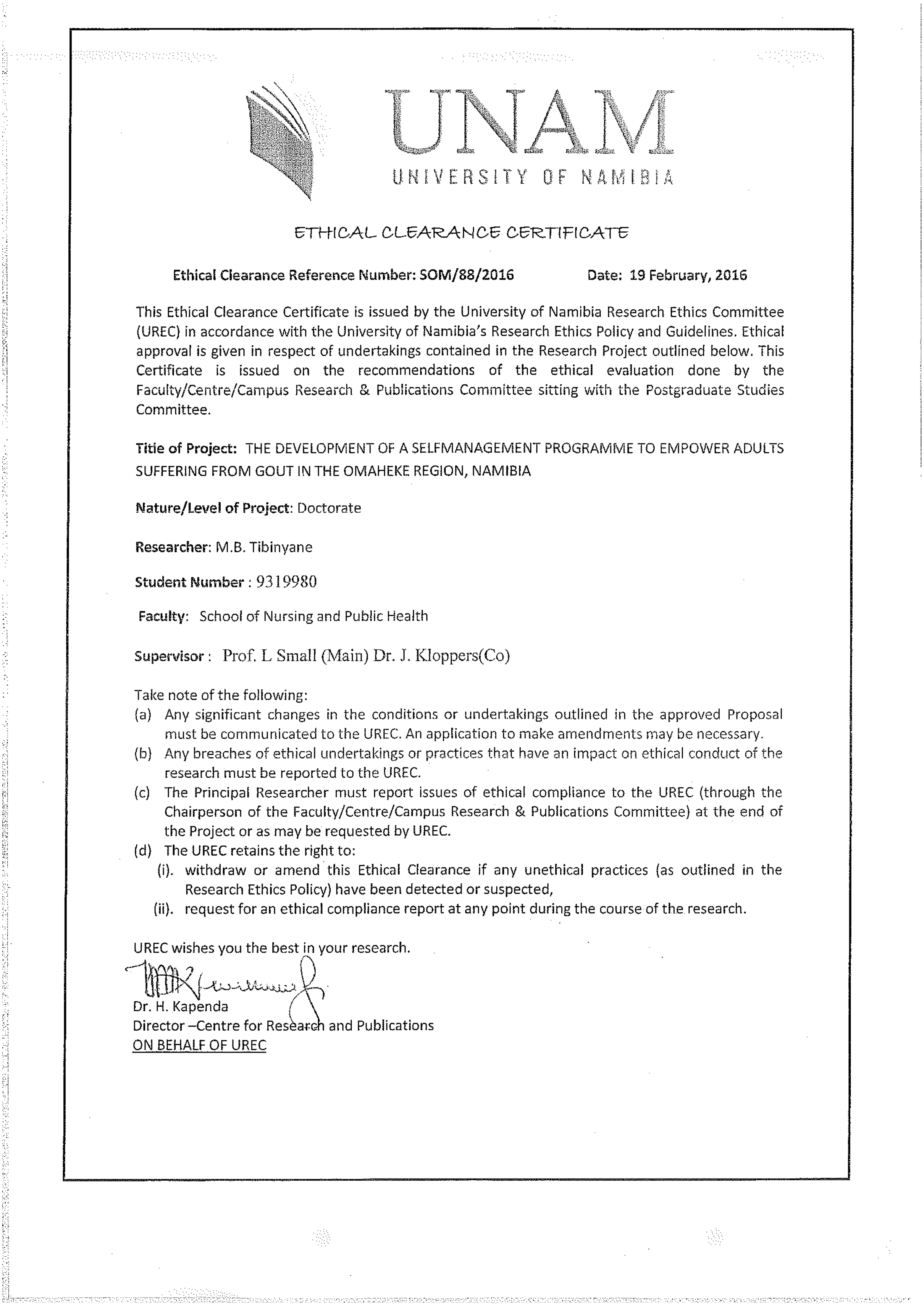
Which social resources have you approached?

Which assistance did you receive?

Which other social resources do you intent to approach?

Appendix A

Ethical Clearance Certficate



UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: SOM/88/2016 **Date: 19 February, 2016**

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: THE DEVELOPMENT OF A SELFMANAGEMENT PROGRAMME TO EMPOWER ADULTS SUFFERING FROM GOUT IN THE OMAHEKE REGION, NAMIBIA

Nature/Level of Project: Doctorate

Researcher: M.B. Tibinyane

Student Number : 9319980

Faculty: School of Nursing and Public Health

Supervisor : Prof. L Small (Main) Dr. J. Kloppers(Co)

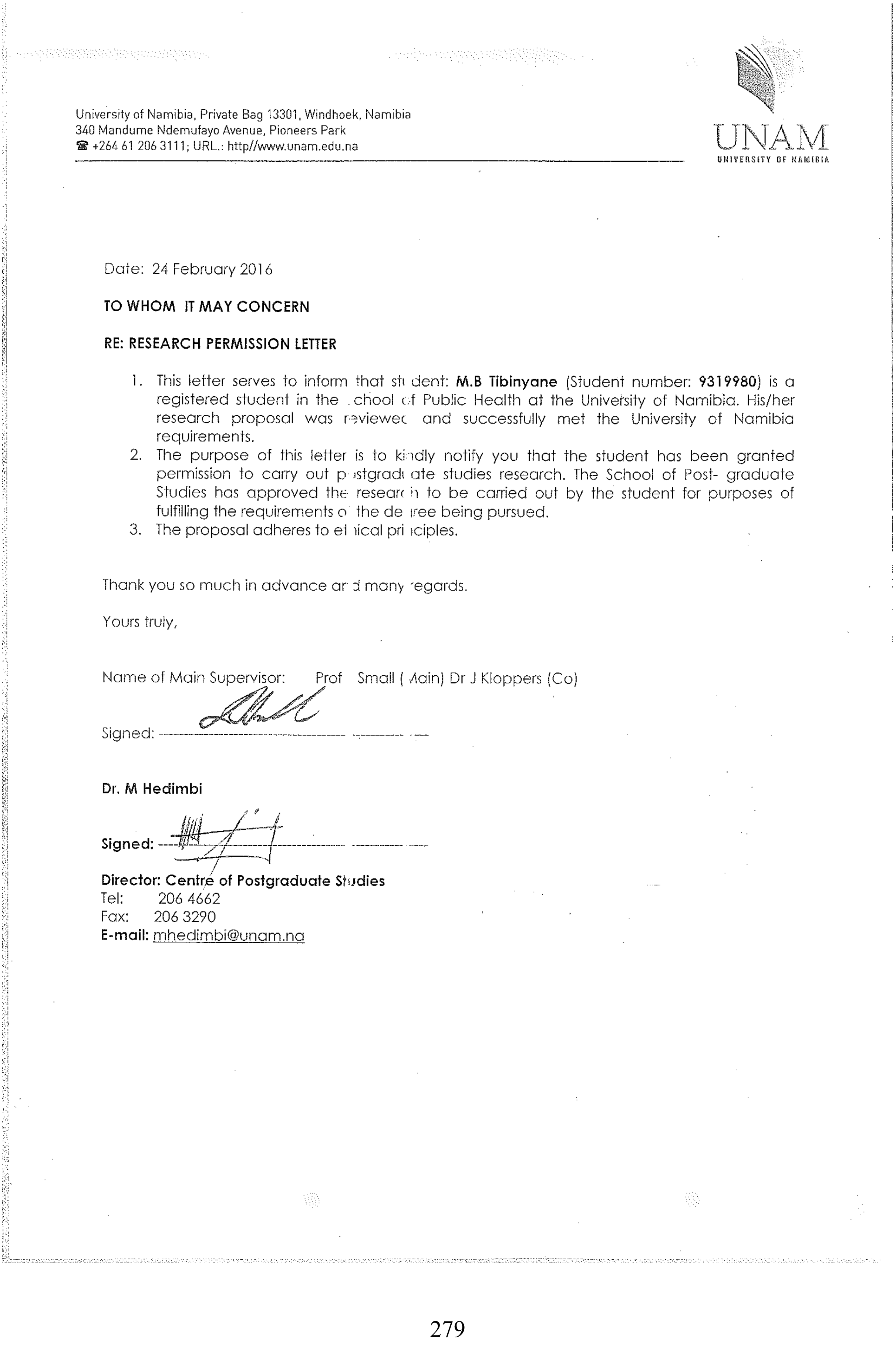
Take note of the following:
(a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
(b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
(c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
(d) The UREC retains the right to:
  (i). withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
  (ii). request for an ethical compliance report at any point during the course of the research.

UREC wishes you the best in your research.

Dr. H. Kapenda
Director –Centre for Research and Publications
ON BEHALF OF UREC

Appendix B

Research Permission Letter



University of Namibia, Private Bag 13301, Windhoek, Namibia
340 Mandume Ndemufayo Avenue, Pioneers Park
☎ +264 61 206 3111; URL.: http//www.unam.edu.na

UNAM
UNIVERSITY OF NAMIBIA

Date: 24 February 2016

TO WHOM IT MAY CONCERN

RE: RESEARCH PERMISSION LETTER

1. This letter serves to inform that student: **M.B Tibinyane** (Student number: **9319980**) is a registered student in the School of Public Health at the University of Namibia. His/her research proposal was reviewed and successfully met the University of Namibia requirements.
2. The purpose of this letter is to kindly notify you that the student has been granted permission to carry out postgraduate studies research. The School of Post- graduate Studies has approved the research to be carried out by the student for purposes of fulfilling the requirements of the degree being pursued.
3. The proposal adheres to ethical principles.

Thank you so much in advance and many regards.

Yours truly,

Name of Main Supervisor: Prof Small (Main) Dr J Kloppers (Co)

Signed: ------------------------------------

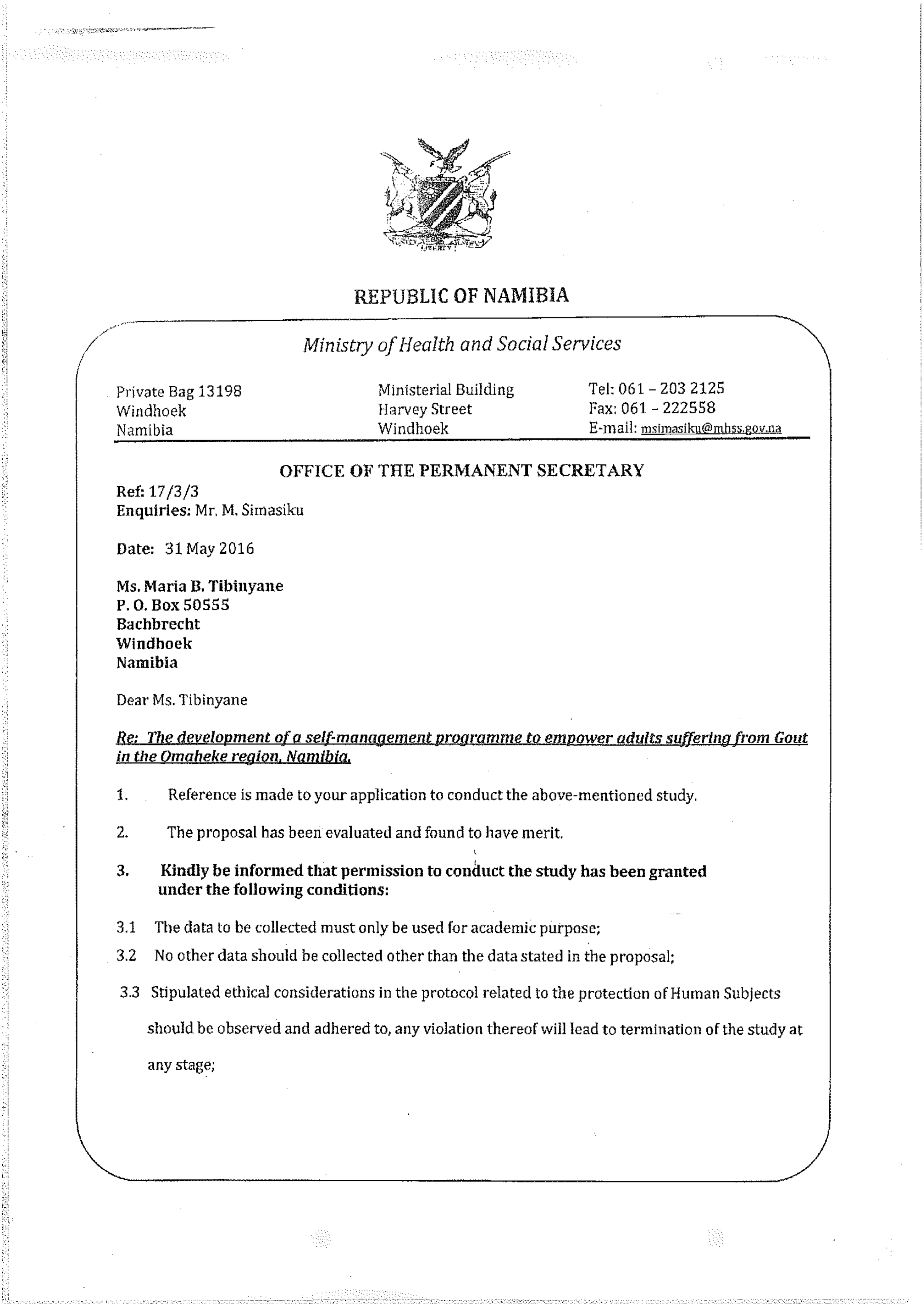
Dr. M Hedimbi

Signed: ------------------------------------

Director: Centre of Postgraduate Studies
Tel: 206 4662
Fax: 206 3290
E-mail: mhedimbi@unam.na

Appendix C

Letter of permission to conduct the study



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2125
Fax: 061 - 222558
E-mail: msimasiku@mhss.gov.na

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3
Enquiries: Mr. M. Simasiku

Date: 31 May 2016

Ms. Maria B. Tibinyane
P. O. Box 50555
Bachbrecht
Windhoek
Namibia

Dear Ms. Tibinyane

Re: The development of a self-management programme to empower adults suffering from Gout in the Omaheke region, Namibia.

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**

3.1 The data to be collected must only be used for academic purpose;

3.2 No other data should be collected other than the data stated in the proposal;

3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;

Appendix D

Adults suffering from gout: Study information sheet

Dear ________________________________ (Name of participant)

My name is Maria Boraunyane Tibinyane and I am registered at the University of Namibia, in the School of Nursing for the degree of Doctoral of Nursing Science.

I hope to conduct a research project in the area of gout flare management and would like to invite you to consent to my including you in my sample of participants that I hope to study at this institution.

The purpose of the study is to explore the lived experiences of the adults suffering from gout. The study is intended to develop a programme that will empower such individuals in the management this condition. Currently there is little documentation in the area on self-management of gout within the Namibian context.

Participation to this study is voluntary. Should you be interested participating in the study, after comprehending the contents of this letter, you will be asked to sign an informed consent form for participation. During the process, you will be asked to share your experiences of suffering from gout as to, among other things how it influence your daily life. It is planned for the interview to be audio taped with your permission; be assured the audio-taped information will be immediately destroyed after transcription to ensure you will never be identified with it. The interview is expected to last for about 40 to 45 minutes. No names will be used in this study to ensure confidentiality and anonymity. There will be no penalties should you wish to withdraw from the study at any point. No harm is anticipated with your participation in this study. There are no direct personal benefits for participation in the study, however it is hoped the shared experiences will provide a basis for making recommendations to higher authorities to support adults suffering from gout. The results of the study will be given to you should you so wish.

Permission to conduct the study has been sought from the relevant authorities such as the Human Research Ethics Committee of the University of Namibia, and the Ministry of Health and Social Services.

Thank you for taking time to read this information letter and should you have any concerns about the study, you may contact me in the Department of Community Health Nursing or on the following e-mail and telephone number: mtibinyane@unam.na and +264 81 278 6486.

Appendix E

Caregiver participants' study information sheet

Dear ________________________________ (Name of participant)

My name is Maria Boraunyane Tibinyane and I am registered at the University of Namibia, in the School of Nursing for the degree of Doctoral of Nursing Science

I hope to conduct a research project in the area of gout flare care and would like to invite you to consent to my including you in my sample of participants that I hope to study at this institution.

The purpose of the study is to explore the lived experiences of the caregivers for gout sufferers at homes. This is intended to identify areas which need support in gout caring as the bulk of gout management is nursing care. Currently very little is documented in gout caring, specifically on caregivers' experiences with the gout flare sufferers within the Namibian context. The findings of this study are therefore expected to highlight areas which need support and more research to advance the quality of caregiving practice in gout flare.

Participation to this study is voluntary. Should you be interested participating in the study, after comprehending the contents of this letter, you will be asked to sign an informed consent form for participation. During the process, you will be asked to share your experiences regarding caring for gout sufferers and the process including your opinion about a gout sufferer caregiver and gout flare as a whole. It is planned for the interview to be audio taped with your permission; be assured the audio taped information will be immediately destroyed after transcription to ensure you will never be identified with it. The interview is expected to last for about 40 to 45 minutes. No names will be used in this study to ensure confidentiality and anonymity. There will be no penalties should you wish to withdraw from the study at any point. No harm is anticipated with your participation in this study. There are no direct personal benefits for participation in the study, however it is hoped the shared experiences will provide a basis for making recommendations to support gout caregiving to the interest of caregivers and others gout flare caregivers. The results of the study will be given to you should you so wish.

Permission to conduct the study has been sought from the relevant authorities such as the Human Research Ethics Committee of the University of Namibia, and the Ministry of Health and Social Services.

Thank you for taking time to read this information letter and should you have any concerns about the study, you may contact me in the Department of Community Health Nursing or on the following e-mail and telephone number: mtibinyane@unam.na and +264 81 278 6486.

Appendix F

Consent form for participation to the study

I ______________________________ give permission to be included in the study titled "A self-management programme to empower Adults suffering from gout in the Omaheke Region"

I have read with the understanding, the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent being included in the study.

Date ____________________ Signature ______________

____

Witness

Consent for audio-tape recording the study interview

I ____________________________________ having received clarification on the purpose of audio-taping the interview, hereby give consent to have the interview audio-taped for the study titled "A self-management programme to empower Adults suffering from gout in the Omaheke Region"

Date ____________________ Signature ______________

____

Witness

Appendix G

Adults suffering from gout: Demographic profile

PARTICIPANTS	DEMOGRAPHIC PROFILES
PARTICIPANT 1	A female pensioner aged 64, affected in the left knee, ankle, toe, both wrists and fingers for 4 years; completed Std. 4. Co-morbidities: Hypertension and obesity.
PARTICIPANT 2	A male pensioner aged 61, affected in toes, right ankle, both wrists, right tarsal, at times fingers are flaring for 10 years; completed Std.4. Co-morbidity: Hypertension.
PARTICIPANT 3	A male pensioner aged 67, affected in the left knee, left shoulder, both ankles, both hands and wrists for 3 years; completed Std.1. Co – morbidity: Kidney failure.
PARTICIPANT 4	A male pensioner aged 71, affected in neck, both elbows, both knees, both heals and both toes for 7 years and has no education at all, never attended school. Co – morbidity: Hypertension.
PARTICIPANT 5	A male communal farmer aged 64, affected in the left toe, both ankles and both knees for 15 years; completed a Master's degree in HR Development. Co – morbidities: Hypertension and obesity.
PARTICIPANT 6	A male commercial farmer aged 62; affected in both knees, both toes and ankles for 25 years; completed Junior education and college education. Co – morbidities: Hypertension and kidneys failure.
PARTICIPANT 7	A female pensioner aged 84; affected in big toes, fingers and feet for 14 years; has never attended school, no education. Co – morbidities: hypertension and kidneys.
PARTICIPANT 8	A male pensioner aged 66 and a tuck shop owner, affected in both toes, wrists, alternative ankles, both elbows and top of both feet for 15 years and completed Std. 4. Co – morbidities: Hypertension, obesity, coronary problems, glaucoma.
PARTICIPANT 9	A male still in employment aged 53, affected in both hands, joints, heels and left toe for 4 years; completed Std.6. Co – morbidities: Hypertension and obesity.

PARTICIPANT 10	A male pensioner aged 63; a tuck shop owner, affected in right elbow, the wrists, right big toe, right knee and top of right foot for 2 years and completed Std. 7. Co – morbidities: Hypertension, obesity and hepatomegaly.
PARTICIPANT 11	A male pensioner aged 63, affected in both big toes, both ankles and both knees for 2 years; completed Std.6. Co – morbidity: glucose in urine.
PARTICIPANT 12	A female pensioner aged 74, affected in both ankles and both big toes for 2 years; completed Std.2. Co – morbidities: Hypertension and obesity.
PARTICIPANT 13	A male pensioner and a commercial farmer aged 62, affected in both big toes, both knees, both ankles and both hips for 27 years and completed Std. 9 (Form 10) with BeTD. Co – morbidities: Hypertension, diabetes and obesity.
PARTICIPANT 14	A male pensioner and a commercial farmer aged 68, affected in the right toe for 6 years; completed Std.10 (matric) plus 2 years Teacher's Education. Co – morbidities: Hypertension, diabetes and obesity.

Appendix H

Caregiver participants' demographic profile

CAREGIVER	DEMOGRAPHIC PROFILE
CAREGIVER 1	A female aged 50, completed Std. 7, and employed as a security guard. Insomnia, hypertension, fatigue and obesity.
CAREGIVER 2	A female aged 29, completed Std. 6, unemployed and has never worked. Fatigue and loneliness.
FGD 1	A female aged 65, a former nurse by profession and a pensioner currently, completed 2 years in nursing education. Hypertension, fatigue and obesity.
FGD 2	A female aged 67, a pensioner and a full time caregiver, who completed Std.4. Hypertension and varicose veins.
FGD 3	A female aged 51, a teacher by profession, with Std.10 and completed BeTD. Hypertension and fatigue.
FGD 4	A female aged 62, completed Std.2, a former kitchen Matron at a boarding school and currently a pensioner. Hypertension and fatigue.
FGD 5	A female aged 64, a former registered nurse by profession and currently a pensioner. Hypertension, fatigue and obesity.

Appendix I

Adults suffering from gout: Interview guide

PARTICIPANT NO…..

I appreciate your willingness to participate in this study which is titled “A self-management programme to empower Adults suffering from gout in the Omaheke Region”.

Very little is published about gout in the Namibian context, specifically on the experiences of suffering from gout and how you deal with the condition. This will be an interactive discussion, so feel free to share your experiences.

What are your experiences regarding suffering from gout?

PROBES

Tell me about when you were first diagnosed with gout. How did you learn about this and what happened next?

In what ways do you think your gout diagnosis has influenced how you go about in your daily encounter with people?

How have you learned to live with the gout condition?

Would you please elaborate on that?

What has helped you come to terms with living the gout condition?

Would you explain how suffering from gout has condition changed your life?

What advice would you give to a person you met who had just been diagnosed with gout?

What advice do you have to offer to the health care arena to help individuals diagnosed with gout?

Appendix J

Caregivers’ interview guide

PARTICIPANT NO…..

I appreciate your willingness to participate in this study which is titled “A self-management programme to empower Adults suffering from gout in the Omaheke Region”

Very little is published about gout in the Namibian context, specifically on caregivers’ experiences of the caring process for people suffering from gout. This will be an interactive discussion, so feel free to share your experiences.

What are your experiences regarding caring for your husband/relative who suffers from gout?

PROBES

As a caregiver you are often the primary contact of this person in the times of great need. Tell me what your feelings are about this?

Gout flare is often perceived as horrible and is further worsened with procedures such as baths and clothing changes. How does this make you feel when you to do all these necessary activities?

Tell me what do you consider to be most challenging about caring for your husband/relative?

Can you tell more how much you are assisted with?

Please tell me what do you do for yourself to cope with this nature of work?

What would you recommend could increase work morale in your daily encounter with your husband/relative.

Will you please elaborate on that?

Is there anything you wish to say that we have not talked about giving care your husband/relative suffering from gout?

Thank you very much for your time. The proceeds of this discussion will be brought to you for validation after formulation of the exhaustive description of your shared lived experience with gout sufferers.

APPENDIX K

Transcript of a 62-year-old adult suffering from gout for 25 years

Key: **I: Interviewer** **P: Participant**

I: Good morning Sir! How are you doing today?”

P: Good morning to you Madam! I am good.”

I: I hope you will still recall that we agreed to meet today to talk about your condition of suffering from gout.

P: Yes, I do remember quite well.

I: OK then! Could you please tell me your experience of suffering from gout? How did you come to know that you have gout?

P: I went for my cousin’s wedding over the weekend, and we had quite a good time.

I felt a pain in my right toe, but I thought it will be OK I might have kicked something;

I: So what happened?

P: Hey! The pain became stronger and stronger until it became unbearable. I took painkillers and applied ointment on the paining toe, but to no avail. I started to cry.

I: Really was it that bad?

P: My two nephews found me crying. When I told them that my toe was really paining and the painkillers and stinksalf were not helping, they already knew what was going on.

I: You said they already knew what was going on? How did they know?

P: Gout is something very common around here, I am telling you. They just picked me up and put my foot in a bucket full of ice cubes. Surprisingly, it was not long and the pain was gone to where it came from.

I: It is amazing. Mmmm, tell me more?

P: Now since they know the pains of gout, one of my nephews said as for him, when the pain starts, the only way he fights it, is to put ice cubes on the foot or put the foot in ice cold water, or even in the deep freezer at home if it comes to a push, imagine.

I: You mean the freezer we put food stuff in?

P: That is correct. He says he's wife can scream and shout as she wishes. The only thing he concentrates on at the said time is, "this Satan must go away."

I: I am listening, please go ahead.

P: It took me quite some time to experience such a feeling and I even forgot about the incident. Then one day I woke up in the middle of the night because I thought something stung me on my right foot.

I: What an experience. So what happened?

P: The experience was extremely painful and sort of scary. I couldn't even dare moving because I imagined the insect that stung me was dormant somewhere in my bed. Mm mm .Mmmm

I: If the experience brings back bad memories to you, please feel free.

P: Okay! As the pain got unbearable, I decided to challenge the pain to get out of bed to look for painkillers, only to realize that I was stuck in my bed.

I: Terrible experience. Didn't you call for help, or were you alone.

P: I was saved by my groaning when I woke up the whole apartment and people came to investigate what was the problem and I got some painkillers. They say it is very hard to eradicate in your system, that it lies dormant. That day I believed that statement

I: Why do you say that?

P: Don't you see? Now both my knees and ankles are affected! I have difficulty in moving around as much as I wish. My friends my age don't walk around with crutches. (Laughing) …This gout thing will make you do things you never imagined.

I: What do you mean? Would you explain more how suffering from gout condition has changed your life?

P: You even hear what is not said at all, people will have their own conversations, the only thing you hear is how they laugh, and all you can think of is hmm! They are laughing at my misery. That is why I say at my place and don't want visitors. I know at times I become impossible with my people around, and regret it most of the time.

I: Are you on any medication?

P: Yes! I am on Cataflam and Diclofenac. And on top of that I was also on high blood pressure medication, exercise and to eat less and ouch! A lot of other don'ts.

I: So I heard. How did you come to terms with dealing with the gout condition?

P: When the pain is gone, and you see people around you enjoying themselves with what you want to quit, there comes the thought of let me just give it a try once more to see whether it's really this that triggers the flair (laughs out loud) and so there is no discipline in controlling yourself against the flair, because food and drinks are delicious looking at it and tasting (scoffs)

I: Okay, is there anything that you would like to say or add on what is happening in your life because of gout?

P: I think I have said quite enough we can go on and on about my experiences with this satanic disease.

I: Thank you for sharing with me your experiences of your illness and have a good day!

P: Thank you too for your interest in me.

APPENDIX L

Transcript of a caregiver

I: Interviewer **P:** Participant

I: Good morning Madam! How are you doing today?"

P: Good morning to you Madam! I am good."

I: I hope you will still recall that we agreed to meet today to talk about how you experienced caring for your uncle who was suffering from gout.

P: Yes, I do remember quite well.

I: Very well! Could you please tell me your experience of caring for your uncle who was suffering from gout? You said he passed on more than a year now. Right?

P: Yes**,** I used to take care of my uncle. His biological children were not interested in helping him, saying that he is a difficult person to deal with. They claim that they are not responsible for his illness and said they have their own lives and own problems to take care of.

I: So, he did not have a wife or a partner to look after him?

P: She passed on way before him. You see my uncle was a brother to my father, taking care of him was not a bid deal for me, I had pleasure in helping him.

I: It sounds like you had a very good relationship, hey!

P: That is where the problem started, you know.

I: What problems did it cause? Tell me more.

P: I was facing problems with his biological children, because when their friends would come to visit them, and I happened to join them, they would say in the presence of their friends: "Get out of here and go sit next to your dearest beloved uncle," making it sound like

I was an intruder. They would point out that their father would not accept their assistance; he only wanted to be assisted by me.

I: That sound pretty bad. Can you tell me more how much you were assisted with?

P: Throughout his illness, none of the family members showed interest in knowing what he needed, what he ate, what the doctors said or even just to know how he was doing or even asking how I was coping taking care of an elder, me being just a child. I would be sitting and sleeping next to him when the flares got him down and he became bedridden.

I: I hear what you are saying, but were you the one bathing, grooming and doing all the self-care activities for him?

P: All of those yes. He wouldn't let them come near him or assist in anyway and would rather wait until I come back from wherever, be it from taking a bath, doing something in the kitchen or from visiting the toilet.

I: Gout flare is often perceived as horrible and is further worsened with procedures such as baths and clothing changes. How did this make you feel when you did all these necessary activities?

P: There were times when my uncle would scream to the point of crying which also made me cry. But as time went by, I got used to the episodes and I think I have hardened to the crying now.

I: I see what you mean. At the beginning you would be emotional, and now you became much stronger.

P: The other big challenge with my uncle's illness was when he had to go to town for the doctors; we would be faced with transportation as my uncle did not have own transport. We would beg for transport or even hire it if no one in the village was already planning to go to town. If he had to be admitted in the hospital, that would be another challenge for me as I had to assist him with bathing, turn him from side to side, feed him, comb his hair; actually do everything for him.

I: Did you have time for yourself at all?

P: Normally I will wait for him to fall asleep before I can do anything for myself, but when he awakes in my absence the first thing he will look for is where I am. Whenever I happen to be away for a short moment from him, he will shout and scream my name if anyone would come near him. In the beginning it was very stressful and frustrating but then I had to accept and endure.

I: If I may take you back, when in hospital, did his children visit him?

P: They would come but only for a short while and not as often as I saw how other patients were visited. The other challenge in the hospital was that I was not getting food as I was not a patient myself, and I slept on the floor on a mattress next to him. My uncle didn't eat any type of food and would skip a meal for me to have it and we would be lucky if one of his friends brought some fruits and juices for him.

I: I understand that you were dedicated to your uncle. Were you able to connect with your friends outside like going for a visit?

P: Not much as the situation sort of restricted me from communicating with my peers and moving around. I had no material, emotional and physical support from anyone, rather my uncle‘s children always found fault with what I did.

I: Is there anything you wish to say that we have not talked about giving care to your uncle?

P: By taking care of my uncle, I had to even cut myself from attending church, because than he would be alone at home. We did not get visits from people in the village itself, but at least on Sundays a priest or Eucharist ministers would come to administer Holy Communion for us and other villagers who would assemble with us.

I: Ummm, wonderful.

P: At that time, we enjoyed having at least some conversation, and that was the only time something else interesting happened. Other visitors coming from somewhere else were those coming to attend funerals or weddings in the village who happened to be his old school friends.

I: What would you recommend for caregivers of chronically ill people to increase work morale in their daily encounter of caregiving?

P: Besides physical and financial support which is also very important, asking how the person or the sick person is doing would lift one's spirit. In my case, my uncle would give me money and insist on not telling anyone about it.

I: As we are about to conclude our interview, is there anything you want to say about what you experienced as a caregiver to your uncle?

P: I think I told you all you wanted to hear. Right now I've got to find myself back to normal life more than a year and 7 months after my uncle passed on. And you are the first person to ask me about what I have just told you. And I thank you for that, Madam.

I: And I also thank you for sharing your experience with me. Have a good day.

P: I thank you too for coming. Have a good day.

APPENDIX M

Transcript of an interview with a 63-year old gout survivor

“My sister I had gout; my whole body was just gout for good 16 (sixteen) years. The only part of my body that was not diagnosed with gout was my brain, ((scoffs)) I’m telling you the true story here. Otherwise every part of my body was just gout, gout and just gout (shaking head, laughing out loud and looking down his pants) even Mr. Private was affected and stressed. He was actually frustrated and depressed, since he couldn’t do anything. My wife suffered same as Mr. Private. You see ((showing elbows)) even the elbows was having sachets due to gout.”

“I stopped beer in 2000, due to gout flare. I moved to Swakopmund recently from the Omaheke Region, because of the weather, seeking for the coastal coolness and moving away from the dry region of ours. I just couldn’t bare the suffering anymore. I took a tough decision of obeying the doctors, since my marriage was also affected by the gout flare. My wife was on the edge of divorcing me if I didn’t adhere to the suggestion of the doctors to move to the Coastal Town.”

“I stopped taking coke, all fizzy drinks and reduced the intake of red meat. I take red meat once or twice a week, and if I want a drink, I’ll take any cool drink except coke but I’ll have to mix the drink with water. The other drink I also got rid of is orange juice, hey those two drinks coke and orange juice, my sister I tell you whether you mix with water, hooooo you are lying if you tell me nothing will happen. Those two drinks are diabolic like this gout flare. I even eat a lot of vegetables, especially greenies. My wife is actually so happy in my changing of diet, because I don’t bother anyone with preparing my meals. I do prepare my veggies myself. If she does, it’s all well, but she knows I can do it myself.”

“Ai tog at this point and time, knowing what I went through with this satanic disease called gout, I must in all honesty admit that I am healed from gout. If we are at a party or any celebration, ((clears throat)) yes I’ll take a glass or two of red wine and it remains there, ((shackles)) the moment I think the party is still on and I take more than two glasses, it is a fight again at night. The pains are back from where, I don’t know. And when they come back, it is the same as the story of driving one devil away and they come back seven of them. Eish. I don’t even for one single moment miss the beer, coke and the unlimited intake of the red meat as I was used to. When that pain comes, I used to think of: “if this was a punishment for living in sin, what will be the punishment of committing grievous sins?” ((Laughing)) and come to think of, when that pain comes, Eish everything and everyone irritates you. You’ll see a passerby talking on the phone ((scoffs)) my dear I’m telling you all I hear him talking about on his phone is telling someone about my gout, even when someone innocently greets me, I just insult that person because all I heard is hi Mr. Gout.”

((Scoffs)) “heeeeeee …. come sleeping time at night, everyone just falls asleep as if there is no patient in the house, even your spouse sleeping next to you has nothing to do with your sleeplessness. Come morning time it’s just a normal good morning story, without how did you sleep or did you even fall asleep? But then comes a moment of breakfast and there is no bread, they’ll immediately know where their dad is for giving them money for bread. Hey, hey, hey, I have suffered oooo….. and then my wife this side is just as much frustrated because there is nothing like meeting as husband and wife, I have really suffered” ((shaking head)).

“If this diabolic thing called gout was to be attacked too, hooooo, just by an attack of one person than the world would have been free from this satanic illness. For now I only feel it sometimes in the ankle but I can manage it. I go for check-ups every month and my doctor is happy with my progress. Before I moved to Swakopmund, I was on chronic medication Puricos, right now I take Colchicine now and then. Otherwise I keep my promise of discipline and self-control. At this said moment, now for 3 (three) years, ((nodding head)) I can tell you that even while the doctors say gout is not curable, mine is cured, knowing what I suffered and the progress of what I am experiencing now, by managing it positively. ((Laughing out loud and looking down his pants)) Mr. Private is back to normal and everyone in the house is happy and there is peace.”

Diets for gout sufferers

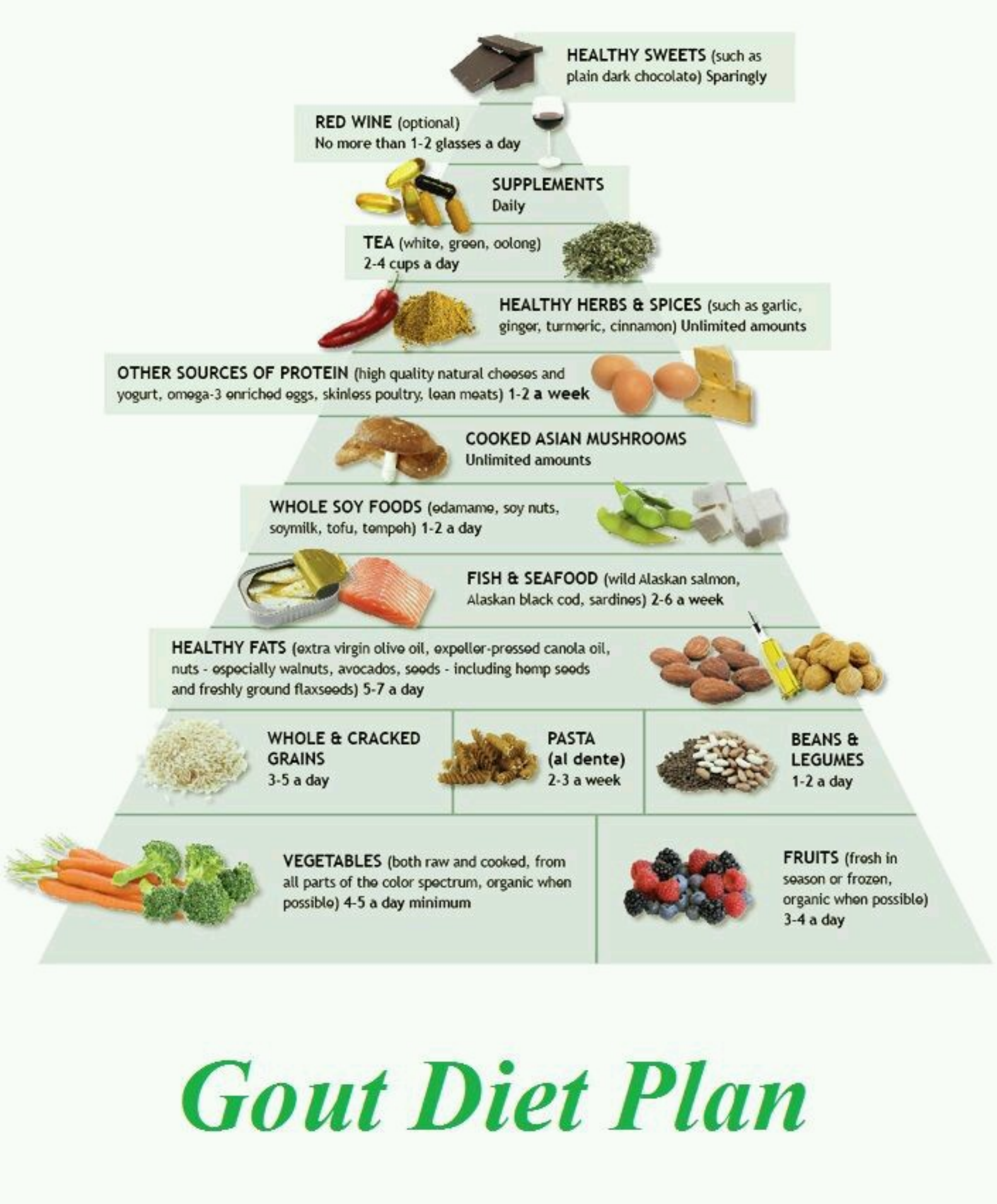


Figure B 1.1

6 RISKY FOODS TO AVOID WITH GOUT

Gout is a form of joint inflammation that is incredibly painful and crippling. Unfortunately, rates are on the rise worldwide, and gout is now **the most common inflammatory arthritis in the US**. This is a list of foods to avoid, based on real scientific evidence.

1. ALCOHOL IS THE BIGGEST RISK FACTOR

Regular alcohol intake severely raises uric acid levels in the blood, and doubles, if not triples your risk of gout. Beer seems to be the worst, followed by hard liquors like spirits. Interestingly, moderate wine consumption is not linked with an increased risk.

2. SOFT DRINKS & FRUIT JUICE

Drinks high in added sugar are associated with an 85% increased risk of gout in men. Fructose is thought to be the nutrient responsible as it stimulates uric acid production in the same way as alcohol. If you want something sweet, diet soft drinks (artificially sweetened) are not linked with gout and appear to be safe.

3. CHICKEN, BEEF & OTHER MEATS

Frequent consumption of meat is linked with a 21% increase in gout risk. The impact of seafood appears far less severe, with a risk increase of 7%. However, it could be beneficial to include high-quality (purine-free) Omega-3 fish oil supplements in your diet.

4. ORGAN MEATS (OFFAL)

Organ meats, known as Offal, contain by far the most purines of any food in the human diet. Given the strong link between meat intake and gout – which is based on purine content alone – offal should definitely be avoided too.

5. VERY HIGH SUGAR FRUITS

A large intake of certain fruits can aggravate gout in those who suffer frequent attacks. While most fruits are very low in fructose, a few are extremely high, such as medjool dates and watermelon. Frequent consumption of these could theoretically causes problems for gout sufferers.

6. ASPIRIN & DIURETICS

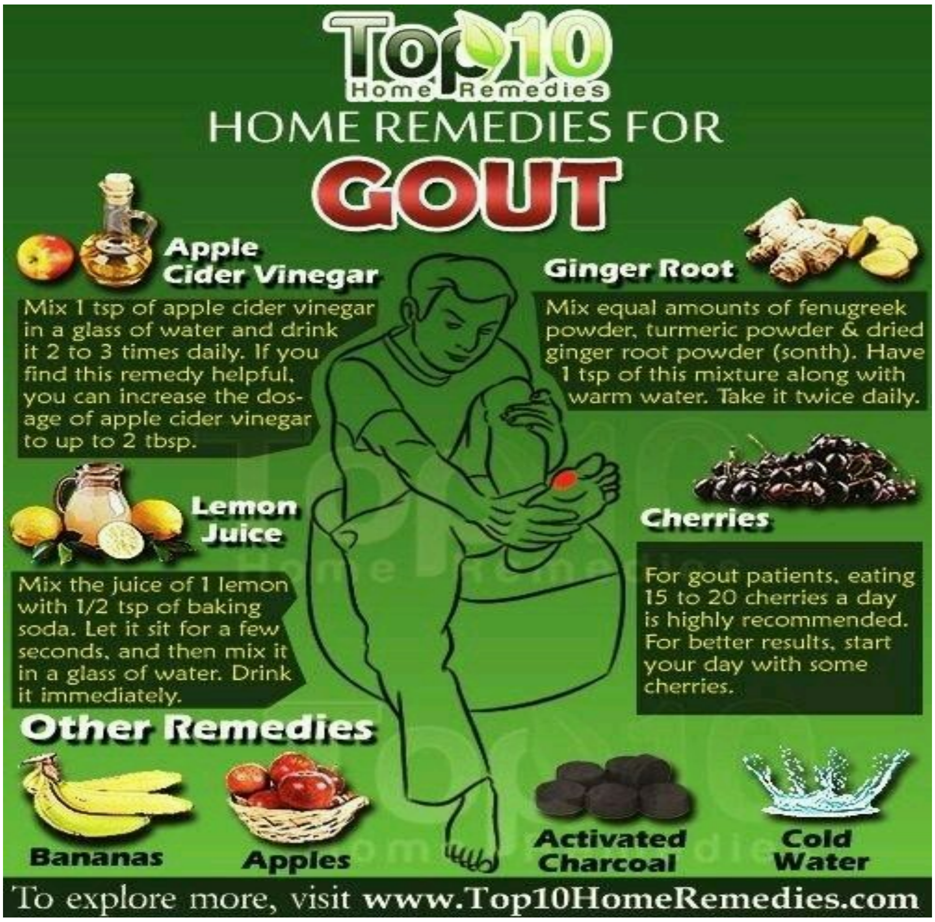
Low dose aspirin is a widely used drug proven to trigger gout, even if taken for a short period of time. Diuretics are also known to increase risk, and if feasible should be discontinued in gout sufferers.

www.DietvsDisease.org
pinterest.com/DietvsDisease

Diet vs Disease

More details & references at
http://bit.ly/avoidgout

Figure B 1.2



HOME REMEDIES FOR GOUT

Apple Cider Vinegar

Mix 1 tsp of apple cider vinegar in a glass of water and drink it 2 to 3 times daily. If you find this remedy helpful, you can increase the dosage of apple cider vinegar to up to 2 tbsp.

Ginger Root

Mix equal amounts of fenugreek powder, turmeric powder & dried ginger root powder (sonth). Have 1 tsp of this mixture along with warm water. Take it twice daily.

Lemon Juice

Mix the juice of 1 lemon with 1/2 tsp of baking soda. Let it sit for a few seconds, and then mix it in a glass of water. Drink it immediately.

Cherries

For gout patients, eating 15 to 20 cherries a day is highly recommended. For better results, start your day with some cherries.

Other Remedies

To explore more, visit www.Top10HomeRemedies.com

Figure B 1.3