THE EXPERIENCE OF SELF OF THE AMPUTEE – AN ECOSYSTEMIC INVESTIGATION

by

ROCHELLE MOUNTANY

Submitted in part fulfilment of the requirements for the degree of

MASTERS OF ARTS IN CLINICAL PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROF. D.P. FOURIE

MAY 2007
Abstract

Amputation patients have a great deal more than just physical recovery to contend with and the extent and scope of this condition is largely unknown in South Africa. Rehabilitation programmes for amputees, specifically at state institutions are characterised by lack of resources, lack of information provided to patients and the patients themselves seem to experience lack of support on an emotional and psychological level.

This study investigates the experience of self of the amputation patient through a review of the literature available and from an ecosystemic-postmodernist viewpoint. In addition, guided imagery is examined as a technique that could add value to rehabilitation programmes for amputation patients.

Health care professionals in two state hospitals in Pretoria were interviewed by means of semi-structured questionnaires to obtain additional information on current rehabilitation programmes as well as the experience of the amputation and the subsequent process for the amputee. Themes extracted from these questionnaires were used to design a suggested rehabilitation programme. This programme, based on the findings of the research, suggests certain enhancements to existing programmes and is focussed on supporting the experience of the process for the amputee through inclusion of specific guided imagery texts.
Acknowledgements

I wish to thank my supervisor, Prof David Fourie for his guidance, patience and support in completing this manuscript, my family – Orpa and Leverne - for their ongoing encouragement and Matthew for the energy burst that was needed at the end.
Table of contents

ACKNOWLEDGEMENTS ........................................................................................................... 3
CHAPTER 1 – INTRODUCTION ................................................................................................. 6
1.1 Introduction...................................................................................................................... 6
1.2 Aim Of The Investigation .............................................................................................. 9
1.3 Research Problem ......................................................................................................... 10
1.4 Value Of The Research ............................................................................................... 11
1.5 Research Method ......................................................................................................... 11
1.6 Research Assumptions ................................................................................................. 13
1.7 Demarcation Of The Study ......................................................................................... 13
CHAPTER 2 – EMBODIMENT AND THE EXPERIENCE OF AMPUTATION ..................... 15
2.1 Introduction.................................................................................................................... 15
2.2 Mind/Body Integration ............................................................................................... 15
    2.2.1 THE POSTMODERN – CONSTRUCTIVIST VIEWPOINT ........................................... 16
    2.2.2 TERMINOLOGY RELATED TO EMBODIMENT ....................................................... 18
2.3 Psychopathology And The Body ............................................................................... 20
    2.3.1 SOMATOFORM DISORDERS .................................................................................. 20
    2.3.2 EATING DISORDERS ............................................................................................ 22
    2.3.3 FAMILY SYSTEMS VIEW OF PSYCHOPATHOLOGY .............................................. 23
2.4 The Amputee’s Experience Of Self ........................................................................... 26
    2.4.1 BODY IMAGE ALTERATION .................................................................................... 28
    2.4.2 ANXIETY ................................................................................................................. 29
    2.4.3 DEPRESSION .......................................................................................................... 30
    2.4.4 POST TRAUMATIC STRESS DISORDER (PTSD) .................................................. 32
    2.4.5 PHANTOM LIMB PAIN ......................................................................................... 32
    2.4.6 SHOCK AND DISSOCIATION ................................................................................. 33
    2.4.7 SEXUAL FUNCTIONING ......................................................................................... 34
2.5 The Impact Of Amputation ......................................................................................... 36
2.6 Conclusion .................................................................................................................... 37
CHAPTER 3 – GUIDED IMAGERY ....................................................................................... 40
3.1 Introduction.................................................................................................................... 40
3.2 What Is Guided Imagery? ......................................................................................... 41
3.3 Benefits Of Guided Imagery ..................................................................................... 43
3.4 Applications Of Guided Imagery .............................................................................. 44
3.5 Conclusion .................................................................................................................... 47
Chapter 1 – Introduction

“I may not have gone where I intended to go, but I think I have ended up where I intended to be.”

-Douglas Adams

“The journey is the reward.”

-Taoist Saying

1.1 Introduction

A large number of amputations are done each year at hospitals around South Africa. An attempt was made to obtain statistical information on the actual numbers of amputations performed in order to relate this better to the psychological impact of amputation on South Africa’s ecology as well as the greater economic impact on the country. Various organisations (Statistics SA, Institute for Medical Research, Department of Labour, Department of Health, Medical Research Council as well as some provincial hospitals) were approached, but no information on amputation could be supplied. It seems that the country is unaware of the impact of amputation on its workforce. This could be a serious oversight and illustrates the apparent neglect of possibly a large percentage of South Africans who experience trauma and loss and are not acknowledged or accommodated.

According to Williamson and Walters (1996) amputations are done for a variety of reasons such as limb deficiency, vascular insufficiency, cancer and traumatic injury.
Desmond and MacLachlan (2002) state that traumatic injury may often be accompanied by Post Traumatic Stress Disorder (PTSD) as a result of the trauma. The illnesses associated with amputation such as diabetes or cancer may also have additional psychological stressors that are related to coping with the illnesses. According to Desmond and MacLachlan (2002), these stressors have an emotional impact, ranging from fatigue, anxiety and low self esteem, to depressive feelings and suicidal ideation.

Amputation patients therefore have a great deal more than just physical recovery to contend with. Desmond and MacLachlan (2002) even postulate than from a psychological perspective the rehabilitation of an amputation patient commences the moment that amputation is considered an appropriate intervention because the anxiety this provokes and the way in which it is dealt with is likely to set the tone for future psychological effects resulting from the amputation.

Many factors influence a person’s adjustment to amputation (Desmond & MacLachlan, 2002; Uellendahl, undated; Williamson & Walters, 1996). Level of functioning prior to the amputation, social, psychological, environmental and physical aspects all play a significant role in the patient’s effective adjustment. These various systems also interact within the living space of the amputee and have a significant impact on the psychological and emotional functioning of the patient.
It is with this in mind that an ecosystemic psychological perspective will be utilised to investigate the research question as this theoretical understanding of how human systems function lends itself to an integrated approach to exploration.

In addition to the emotional, health and psychological impact of amputation, there are also economical factors to consider:

“Rehabilitation is expensive and resource intensive and does not easily capture public and legislative interest. The outcome of rehabilitation cannot be accurately predicted in each case, and its outcomes have been less well measured than other areas of health care. This poses a special cost-benefit problem.” (Callahan, 1995, p. S7).

The impact of amputation on the South African economy and specifically the health sector is largely unknown. Health services programmes are subjected to regular evaluations in developed countries, but this has not yet become common practice in South Africa. It is predicted that the worldwide changes in these programmes focussed on rehabilitation and health care will eventually develop into a consumer driven system where outcomes are the main goal (Chesson, Macleod & Massie, 1996; DeLisa, Granger & LaBan, 1993; Gonella, 1992).

The amputation rehabilitation process in South Africa and specifically in Gauteng, seems to be characterized by a huge demand with lack of resources and poor definition of
objectives. In addition, it also seems based almost entirely on the physical recovery of the patient and takes little psychological or emotional adjustment into account.

Psychological and emotional support that does occur seem to be incidental to the process, depending largely on the personality of the caregivers and physical therapists (Occupational and Physiotherapists) as well as the family’s pre-morbid functioning. Professional psychological help is therefore rarely included.

1.2 Aim of the investigation

Desmond and MacLachlan (2002) state that rehabilitation after amputation is fundamentally dependent on the amputee’s psychological adjustment to his/her amputation. It would seem as if most rehabilitation programmes focus on facilitating physical adjustment to the amputation and prosthesis. Studies around the adjustment of amputees also concentrate on physical factors that facilitate or impede the adjustment process (Kent & Fife, 1999; Pohjolainen & Alaranta; 1991; Sherman, 1997), affording little consideration to factors related to the psychosocial impact of amputation (Grise, Gauthier-Gagnon & Martineau, 1993).

This study continues with the concept that the experience of self of amputation patients in relation to their psychosocial environment can be seen as a significant factor influencing the success of their rehabilitation. It therefore proposes that a reframe of the experience of self of such patients may aid rehabilitation and influence the psychological well-being
of the patient to a large degree. Because of the lack in structure of psychological support offered in conventional rehabilitation programmes, a psycho-educational rehabilitation programme will be compiled. The development of this programme will rely on investigation of the experience of amputees as reported in the literature as well as on reports from health care professionals working in the field of amputation. The aim will be to structure the programme in such a way that it may be presented by any health care worker in order to best utilize the possible resources available.

1.3 Research problem

The research focuses on the experience of the self of amputees in adjusting to their psychosocial environment. The aim of the study is to gather sufficient information with regard to the ecology of the amputee so as to present a rehabilitation programme that includes a greater sensitivity to the psychological and social stressors emerging after amputation. Specifically, the use of guided imagery in enhancing a positive body image and therefore a more integrated sense of self is presented as a possibility toward facilitating more effective adjustment to amputation.

Amputation refers to the cutting off of a limb, or part of a limb, the breast or other projecting part (Stedman, 2000). This cutting may be applied to an upper extremity in which case it is referred to as either below elbow or above elbow amputation. In the case of lower extremity amputation, it can occur as a syme (ankle), below knee, knee
Disarticulation or above knee procedure. No distinction is made in this investigation between various forms of amputation.

1.4 Value of the research

It is hoped that this research will assist in the improvement of the efficacy of current rehabilitation programmes. This in turn would have an impact on the expenditure for patients who return to these programmes due to difficulty with initial adjustment. The expected reduction in the risk for the development of psychological disorders such as depression not only would have a positive impact on the patients, their families and work environments, but would also reduce the need for subsidized medication and treatment at state institutions.

The proposed psycho-educational rehabilitation programme is so structured that any health care worker may be utilized in the presentation of the programme, thus enabling health institutions to empower their workforce and use their resources effectively.

1.5 Research method

A literature study has been conducted into the stated problem. Not a great deal of literature seems to be available with regard to the adjustment of patients to amputation and the impact of amputation on the individual. The few studies available are used to elucidate the impact of amputation on the individual and speculate about the impact of
the amputation on the individual’s ecology. This includes self-reports from amputation patients and studies conducted on various aspects of the psychosocial impact of amputation.

In addition, use was made of semi-structured questionnaires completed by professionals involved in the rehabilitation process of amputation patients. This was done in order to ascertain their views on current practices as well as their opinions on the value of increased psychological focus in a rehabilitation programme. Themes have been extracted from these questionnaires that have been used during the development of the suggested rehabilitation programme with the aim of developing a programme that may be more effective than some currently in use.

As a rehabilitation programme with greater focus on support of psychological factors through, amongst others, the use of guided imagery is proposed, an investigation in the form of a literature review into the nature and use of guided imagery is presented to elucidate this concept.

The research is conducted from an ecosystemic constructivist paradigm where the amputees are considered as systems within themselves that function within a greater ecology. True to the nature of post-modernist thinking, the reality of the amputation patient is considered of greatest importance throughout the study, as the impact of guided imagery may only be effective when working within the life-world of the amputee.
1.6 Research assumptions

It is assumed that improved emotional and psychological well being of amputation patients will have a positive effect on their overall rehabilitation. It is further assumed that a supportive informed system could encourage their emotional improvement and therefore assist in rehabilitation and that this system could consist of any member(s) of the patient’s ecology.

The patient’s ecology is seen as the psychological and social life-world of the individual. This includes life partners, family members, care givers, health professionals and colleagues. It is further extended to also include additional factors specific to amputees, such as a prosthesis, physical limitations in mobility and events where the amputee’s personal space becomes compromised.

1.7 Demarcation of the study

The study embodies a literature review of the experience of amputees as related to sense of self. A literature review on the use of guided imagery in a medical and psychological context is also presented. In addition two rehabilitation programmes are evaluated by means of semi-structured questionnaires completed by the health care professionals involved in these programmes. Interviews have not been conducted with amputees as a greater body of knowledge is available in literature sources than is likely to be obtained from the limited scope of amputees the author would have access to.
The study does not aim to investigate the impact of the suggested programme because of the limited scope of the dissertation and the time available. Further research may be useful in this area as the applications may not only be limited to amputation patients.

The study conducted as well as the recommended rehabilitation programme do not distinguish between various forms of amputation but do assume that certain amputations have worse effects on patients than others and that these patients may require additional psychotherapy.

The next chapter presents the literature review of the amputee’s experience of self as well as the more general concept of embodiment and the implications this has for psychological wellbeing.
Chapter 2 – Embodiment and the experience of amputation

At the centre of all communication rests the body, the fleshy gateway to the mind (Biocca, 1997, p. 58).

2.1 Introduction

This chapter explores the concept of embodiment as seen from a social as well as from a psychological and pathological perspective. The link between mind and body is investigated, specifically as it occurs within the field of psychopathology. Furthermore, attention is given to the experiences of amputees as reported in the literature, allowing for a picture of the experience of amputation to emerge.

2.2 Mind/Body integration

The separation between body and mind, which has been so prevalent in Western science since the time of Descartes (Tarnas, 1991), has also strongly influenced the development of modern medicine and general psychological approaches to health care (Peper, Ancoli & Quinn, 1979). Society has progressively relegated everything roughly below the neck to physicians, while psychiatrists and psychologists were entrusted with functions above the neck. Individual aspects outside the body have been thrust upon the clergy.
In recent years a move away from this modernistic world view toward a post-modern world view has become prevalent. Man has begun questioning modernity and its attempts at finding ultimate truths through defined methods and practices (Wilson, 1997). More attention has been focussed on the postmodern movement, which is invested in rejecting an idealised view of ‘Truth’ and replacing it with a dynamic, changing truth bounded by time, space and perspective (Wilson, 1997).

2.2.1 The postmodern – constructivist viewpoint

Whereas postmodernism can be seen as an underlying philosophy about the world, constructivism is seen as a theory of cognition, of how we come to know things. The roots of many constructivist concepts are traceable to postmodern ideas and philosophies (Wilson, 1997). The value of this perspective allows us to consider the world view of the amputation patient as his/her truth in order to establish how amputation is experienced.

At the essence of the postmodern – constructivist viewpoint is the belief that knowledge and meaning are constructed between people (Hlynka & Yeaman, 1992). There is an acknowledgement of a plurality of perspectives and there is allowance for multiple truths. This viewpoint also considers thinking and perception as inseparable (Hlynka & Yeaman, 1992). Through the eyes of the postmodernist – constructivist approach, we are therefore able to investigate the experience of an occurrence as it is felt by the person going through the experience. This person’s perception of the experience and the way in which he/she ascribes meaning to it may then be considered as a truth about the occurrence, i.e.
it is possible that others within the same context would interpret the occurrence in the same way and have similar meanings ascribed to it, or not.

One of the aspects central to this study is the link between mind and body. From a modernistic viewpoint in the medical sciences, the mind and body have traditionally been regarded and treated as separate. Health care workers have, however become more aware of the artificial nature of this separation and are acknowledging what people throughout the centuries have intuitively known: mind, body and spirit act in unison and disruptions in one aspect often go along with disruptions and symptoms in one or more of the others.

How often do people experience this phenomenon in daily life? A headache during a tension filled day. A cold when stressors come to a peak. Stomach ulcers around anxiety experienced over an extended period of time. A euphoric mood and a glowing countenance when one is in love. The physical and situational circumstances feed off one another, creating a situation in which mind and body cannot possibly be considered as separated. All these aspects are a part of the human experience, yet medical science has, in the past, paid very little attention to this and the Cartesian model of thought remains largely prevalent.

In the following sections, the relationship between mind and body will be examined using more formal examples to elucidate their interaction. This is then extended to the experience of amputation as reported by the amputees in the literature. To facilitate understanding, firstly some terminology related to the bodily experience will be clarified.
2.2.2 Terminology related to embodiment

- **Body image**

Body image can be defined as the mental picture a person forms of his or her physical self (Breakey, 1997). According to Breakey (1997), each individual holds an image of the body that he or she considers the ideal in relation to his or her own body. An alteration in a person's body image interacts in a dynamic way with a number of emotional, perceptual and psychosocial reactions. Loss of a limb through amputation is likely to lead to a disorder in body experience which is often found to be long-term (Breakey, 1997).

- **Body image boundaries**

The experienced boundaries of the body do not necessarily involve the actual physical material it consists of, but may at times extend further or even exclude this matter. This may be observed in phantom limb pain occurrences where an individual experiences feeling and even excruciating pain in the area of a limb that has been amputated. In some psychiatric illnesses, referred to as somatic disorders, the client often has a physical symptom that could extend as far as losing the use of a limb without any physical disability. In cases such as body dysmorphic disorder as well as in eating disorders, a distorted image of the body is often experienced.
• Sense of self

There are many words in the English language that reflect a sense of self as related to a body image: embody, personify, embodiment. Is it any wonder that we place such high values on our bodies when we consider how the concept has impregnated our language imagery? Sense of self is assumed to be so closely linked with body image that the two concepts can almost not be separated as there is a constant interaction between them.

Sense of self can therefore be seen as a function of a person’s body image because it is an experience of mind, spirit and body. It is integrated into the human experience of embodiment, linking the physical with the emotional and ultimately translating into the impression we each carry of ourselves.

• Experience of self

‘Experience of self’ and ‘sense of self’ are two closely linked concepts. ‘Sense of self’ can be seen as informing the process of ‘experience of self’ – ‘sense of self’ can therefore be seen as a relatively static concept, while ‘experience of self’ can be seen as dynamic, interacting with all aspects of self. Experience of self incorporates all aspects with regard to the experience of existence. This includes a person’s spiritual, physical, psychological and interpersonal dynamic and life experience. How someone sees him/herself, how he/she reacts to people and situations and how he/she thinks of him/herself in his/her innermost private thoughts will reflect his/her experience of self.
2.3 Psychopathology and the body

Various psychiatric diagnoses imply a link between mind and body. Although the amputee’s adjustment to amputation is not here considered as a psychological or psychiatric disorder, it could be useful to investigate briefly the possibilities of pathology with which the link between mind and body can be associated. It is also of importance to consider the role of psychopathology in family systems as this could elucidate the role of amputees within their systems as in both cases the individuals concerned are ultimately different and are treated and reacted to as such.

There are many fields in psychology that directly relate a psychological condition to a bodily symptom or experience. The somatoform and eating disorder groups are examples that give background related to the severe extent to which the mind-body connection can have an impact on human functioning. They are briefly mentioned below in order to elucidate the scope of possibilities involved when sense of self and body image are involved.

2.3.1 Somatoform disorders

Somatoform disorders are related to bodily (‘soma’) symptoms that cannot be fully explained by a medical condition or substance use and are therefore thought to have a psychological basis that translates itself into physical symptoms (Kaplan & Sadock, 1998). In family systems theory, the symptoms are seen to have a role within the family
system. Chronic pain is often seen to gain rewards such as attention or deflecting attention, or to disclaim responsibility (Sue, Sue & Sue, 2002). In all cases, however, the people experiencing the symptoms believe that they are real and although no physiological basis exists for the complaints they are not believed to be voluntary on under conscious control.

Various distinctions are made within the category with five main disorders identified. These are:

- **Somatization disorder:**
  Characterised by multiple physical complaints related to pain, gastrointestinal, sexual and pseudoneurological symptoms.

- **Conversion disorder:**
  Characterised by the presence of one or more neurological symptoms that involve loss or alteration of physical functioning such as paralysis, blindness and mutism.

- **Pain disorder:**
  Pain on one or more sites of the body is the predominant focus of clinical attention.

- **Hypochondriasis:**
  Characterised by the preoccupation with fear of contracting or belief of having a serious bodily disease.

- **Body dysmorphic disorder:**
  Characterised by a preoccupation with an imagined defect or distortion of a
minimal defect in physical appearance of a normal appearing person (Kaplan & Sadock, 1998).

Another group of psychiatric conditions related to an individual experience of body and how this translates to a sense of self, are the eating disorders.

2.3.2 Eating disorders

Body image and self-esteem have become inseparably intertwined in modern society. Contempt of oneself and disturbance of body image are often seen in those that struggle with weight control issues (Freedman, 1990). Eating disorders have a strong self-image component that relates to the individual’s entire functioning (Cross, 1993).

The following distinctions are made within the eating disorders category:

- **Anorexia Nervosa:**
  Characterised by a refusal to maintain a normal body weight, an intense fear of gaining weight and a significant impairment in the interpretation of the body and its shape.

- **Bulimia Nervosa:**
  Characterised by binge eating combined with inappropriate ways of halting weight gain. Feelings of being out of control often accompany this condition (Barlow & Durand, 1995).
From the psychological disorders mentioned above, it is clear that the link between mind and body can be very powerful and changes in one aspect could have far reaching effects on the other. We remain unclear about the extent of this link and the multiple ways in which it may be utilised. As with any system a change in one aspect, the body, is likely to have an impact elsewhere. It is therefore no coincidence that an amputation patient can experience disturbance of mood and alteration in state of mind.

In both cases (somatoform and eating disorders) the individual is faced with some sense of loss of control. Regardless of the etiology of the condition, the person is faced with profound issues around body image and the control of his/her experience of self. This experience then translates to physical attributes or behaviours, which in turn can be seen as reinforcing the original experience. In the same way, an amputee, who is likely to have a disturbance in body image, could develop serious psychological disturbances around this disruption.

2.3.3 Family systems view of psychopathology

According to Sue et al. (2002), the family systems view focuses on an individual’s behaviour as part of the family interaction. Psychopathology in this system is then often seen as a symptom of the larger system and is not viewed as residing within an individual. This view supports Keeney (1984) in his explanation of the idea that systems are organised through the process of change. A healthy individual responds to a changing situation with a complex set of diverse behaviours and emotions. This person
may shift between love, hate, despair and hope in order to maintain balance in the changing process. In the same way, pathology may be viewed as an attempt at achieving stability during the process of change by escalating behaviour and emotions (Keeney 1984). In this way, the unhealthy individual, within an unhealthy family context, may for example, respond with deep despair (depression) or extreme elation (mania) in an attempt to maintain stability within a changing context. These behavioural changes are not considered as deliberate but can be viewed as an involuntary, almost instinctive, reaction to the changes in the system. Incidentally, exposing these dynamics are often the only therapeutic intervention required in addressing such a dysfunctional situation.

Abnormal behaviour within a family system is often regarded as a reflection of unhealthy dynamics within the family or of a dysfunctional communication system (Sue et al., 2002). It is important to keep in mind that family systems theory does not point to a causal link but rather investigates the dynamic interplay of elements. As with the somatoform disorders, the systems view can often distinguish a systemic reason for the person to present with physical symptoms. It may be that verbal communication within the system becomes ineffective and attention is only paid when a physical ailment crops up. The system is then likely to react differently than before (attempting to maintain stability through the change), be it to rally around this ‘symptom’ or around the symptomatic person, or alternatively the dynamics of the system could change to divert attention to the symptomatic person, away from a conflict laden situation.
People afflicted with an eating disorder often feel a lack of control over their environment (usually their family system) and therefore resort to controlling the only aspect they perceive to have mastery over: their body. The more the family system then attempts to control them, and their unhealthy behaviour, the more they are therefore likely to retreat further into their own bodily control, exacerbating their condition. Sadly, this dynamic often spirals so far, that total control is taken away from the symptomatic person when he/she needs to be hospitalised due to the physical condition and he/she ends up having to ‘earn back’ the right to have own responsibilities.

The person who has undergone an amputation has not only to contend with physical recovery and adjustment, but also with the psychological impact related to himself/herself as well as the impact the amputation has on his/her ecology as a whole. The extent and ease of recovery will also largely be dependent on the functioning of the ecology prior to the amputation and the system may need to be equipped with ways in which to handle this additional stressor.

Viewed systemically, the amputee’s life world can be regarded as many systems that interact, with the central character, the amputee, undergoing a fundamental change. The effects of this change will ripple through all these connected systems in various ways. According to the constructivist view, the meaning constructed from the dynamic between these various systems and the amputee informs the experience of self of the amputee.
Embodiment seems to receive more focus as society becomes increasingly sentient. That is to say, as we become more aware of ourselves, our impact on one another and on our environment, we also become more self-aware and tend to focus more on how we come across and how we view ourselves and our contemporaries. At no other time in history has the fashion and beauty industry been so prevalent in society (Wolf, 1991). Our bodies and indeed our entire experience of self is on display and under the microscope more than ever before.

Progressive embodiment also seems to be part of a larger pattern, involving the cultural evolution of humans and their communication artefacts towards a mutual integration and greater ‘somatic flexibility’ (Bateson, 1972). Simply put, we are becoming more aware, from simple cave paintings of stick men, to the languid paintings of the Renaissance to the fashion features in magazines and sometimes very explicit depictions of humanity in film and television. We are able to incorporate more bodily awareness into our daily living simply because we are constantly bombarded by features of embodiment. It is likely that within this context the amputee would have greater difficulty in adjusting to bodily changes than during past times when society placed less emphasis on physical beauty. The psychological effects of amputation are therefore also likely to be amplified.

2.4 The amputee’s experience of self

As stated by Desmond and MacLachlan (2002), adjusting to amputation is likely to coincide with a variety of psychological stressors but very few studies relating to the
rehabilitation of amputees and their experience of themselves can be found in the literature. An attempt is made here to explore the various aspects that impact on the amputee’s experience through some of the studies available as well as from published self-reports from amputees.

From the literature it seems clear that the amputee’s different physical body links with an adjusted body image. The aspects related to sense of self that seem most likely to be experienced as part of the difficulty in overcoming the impact of amputation include:

- Altered body image
- Anxiety
- Depression
- PTSD
- Phantom limb sensation
- Shock and dissociation
- Sexual functioning

Each of these experiences have been reported in the literature as profoundly affecting the amputee and influencing the experience of amputation and ultimately of him/herself. These experiences are set out below with examples from reports of amputees elucidating the nature of the experience.
2.4.1 Body image alteration

Body image is a dynamic construction, subject to continual deconstruction, revision, and reconstruction in response to both internal and external stimuli (Desmond & MacLachlan, 2002). The experience of amputation disrupts this construction and is subsequently associated with varying degrees of alteration in body image and ultimately in sense of self.

Breakey (1997) postulates that the perceived discrepancy between the altered physical state and the former physical state produces emotional tension. In their extensive body-image survey, Cash, Winstead and Janda (1986) included several items they identified as comprising psychosocial well-being. These items addressed self-esteem, life satisfaction, depression, loneliness and feelings of social acceptance. Persons with positive evaluations about their body image reported favourable psychological adjustment. In contrast, those with negative feelings presented lower levels of psychosocial adjustment.

Reconceptualization of body image after an amputation requires the incorporation of both the loss of the limb as well as probable phantom sensation of the limb, and in some cases the incorporation of prostheses, canes, and crutches into the body image. The amputee therefore not only has to adjust body image according to changes in the physical body, but in many instances has to incorporate inanimate objects into this image. Fishman
(1959, p. 324) sums it up succinctly when he states that a person “must learn to live with his perceptions of his disability” rather than “with his disability”.

2.4.2 Anxiety

Anxiety may be present in the amputee’s system even prior to amputation. The reason for amputation, be it trauma or illness, is likely to have taken its emotional toll by the time that amputation is considered as a suitable intervention. Subsequent to this, the actual amputation operation is likely to evoke high levels of anxiety. Broadhurst (1989) documented the emotions of an amputation patient, Paul, throughout his amputation experience. Paul’s anxiety seems to be more evident prior to the operation, as he states in his diary:

Day 3
“I want it to happen as quickly as possible, at the same time hoping it takes a long time for Friday to come. I know if it works I can lead a normal life...But it still doesn’t alter the fact that I was born with two legs and expected to die with two legs.” (Broadhurst, 1989, p. 56)

Day 4
“Although I had plenty of visitors again and it took my mind off the operation, I’m getting worried. Will it work? I know I’ve got no choice.”
Everyone keeps telling me it will work, and I will be all right, but it’s not the same. It’s not their foot.” (Broadhurst, 1989, p. 56)

A variety of other reasons for anxiety are present within the amputee’s system. Anxiety as a result of expected impact of the amputation, anxiety as a result of reactions of friends and family to the amputation as well as internal anxiety related to physical change and the amputee’s emotional reaction to this.

2.4.3 Depression

Depression is often experienced after the loss of an object of value. Sue et al. (2002) also cite research that has found stress to trigger a depressive episode. Due to the severe impact that an amputation could have, as well as the stress related ecological implications of an amputation, the amputee is at great risk of developing this condition.

Sue et al. (2002) pontate that depressive episodes and the associated negative self-images may reduce coping skills in individuals that may lead them to situations that result in further depression. It would seem likely then, for a negative downward spiral to develop that could drag the emotions of the amputee down into depths of despair, reinforced at every turn not only by his/her own image of him/herself and the physical evidence of his/her misfortune but also by the reaction of his/her larger social ecology.
Parkes (1976) reports having interviewed 46 amputees four to eight weeks after their operation and again 13 months following amputation, asking 18 questions to detect depression. Moderate disturbance was shown by approximately 40 percent of the subjects. This disturbance continued a year later. Feelings of insecurity, self-consciousness, restlessness and depression as well as insomnia were reported by 25 percent of the group. These symptoms were consistent from the first to the second interview. Additionally, as a group, the amputees' levels of depression, as indicated by test scores 13 months after the amputation, were twice as great as those of nonamputee U.S. men and women of the same age.

Paul’s diary (Broadhurst, 1989) gives some insight into the personal experience of the amputation patient’s depressive mood. Paul also states that he feels angry – a common manifestation of depressive mood in males.Immediately after the operation (Day 5 in his diary) Paul’s emotions are still slightly numb and he only feels “a slight sadness” for himself. By Day 11 however, his reaction to the amputation is dramatic:

“I felt sick and on return to the ward I did not want to talk to anyone or do anything. Felt really low and depressed at the same time as feeling empty and extremely angry with myself as I had always said I wouldn’t get like this. I don’t know what is worse – the depression or the anger.” (Broadhurst, 1989, p. 57)
2.4.4 Post Traumatic Stress Disorder (PTSD)

As previously mentioned, amputation is often the result of a traumatic incident that is accompanied by other aspects. One such feature prevalent among victims of traumatic accidents is Post Traumatic Stress Disorder (PTSD). The features of this disorder include re-experience of the event in dreams or intrusive memories, emotional numbing and avoidance of stimulus associated with the trauma, as well as heightened autonomic arousal (Sue et al., 2002).

In the case of amputation patients, treatment of PTSD may be more challenging than with other victims of trauma because the amputee has a constant physical reminder of the trauma. Additional stressors (such as anxiety and mood symptoms) are also present that could heighten the person’s anxiety levels which could in turn promote flashback experiences or recurring dreams.

2.4.5 Phantom limb pain

According to Willoch, Rosen, Tölle, Øye, Westner, Berner, Schwaiger and Barenstein (2000), nearly all amputees experience vivid phantom limb sensations and up to 66 percent of these people experience the pain even 25 years after the amputation. The experience of the phantom limb often involves sensations such as movement and
differing positions of the amputated limb as well as the experience of severe pain in the
limb that has been amputated.

Paul (Broadhurst, 1989), started to experience these sensations quite soon after his
amputation and muses on this on Day 18 of his diary:

“Pins and needles in my toes are getting worse; it seems stupid that the
brain can be told that the foot is not there, while the nerves still feel the
toes.” (Broadhurst, 1989, p. 57)

2.4.6 Shock and dissociation

It is important to keep in mind that not all amputation patients are aware of the operation
awaiting them. In the event that trauma is sustained, the patient might be unconscious
and need to receive emergency surgery. In such cases, the shock of the traumatic
incident as well as waking up after the operation with an amputated limb is conceivably
enormous.

The impact of the amputation, even with prior knowledge of the operation, is often very
different from the expected impact. This is also illustrated in Paul’s diary two days after
his operation (Broadhurst, 1989):
“Although I only saw the stump for about five minutes before it was re-bandaged, it suddenly became very personal rather than impersonal, and for a few moments I felt dreadful…” (Broadhurst, 1989, p. 56)

As a result of shock and attempts at dissociation from the pain, the amputee is likely to come across as self-isolating and may attempt to keep close friends and family at a distance. This reaction is likely to have an isolating effect on the amputation patient, jeopardising the supportive environment that a care-giving system could offer.

Paul started to experience a certain emotional numbing on Day 13 and again briefly alludes to the isolating act of pretending for the sake of his family that he is coping emotionally:

“…I tried to put on a happy face, but I felt slightly empty inside…”

(Broadhurst, 1989, p. 57)

2.4.7 Sexual functioning

Williamson and Walters (1996) related amputees’ perception of self to sexual functioning. In their study high levels of perceived negative impact of amputation on sexual activity were found which correlated strongly with symptoms of depression. Some participants in their study offered the following:
From a 36 year old above knee trauma amputee, described by the interviewer as muscular and attractive: “I just don’t feel like the man I was…She’s been pretty good about it (referring to his live-in partner). I just don’t know if I could be.” (Williamson & Walters, 1996, p. 227)

From a 69 year old divorced man with above knee amputation: “Few people are completely at ease with the nitty gritty of any disability.” (Williamson & Walters, 1996, p. 227)

From a 34 year old single (never married) man who had lost both legs below the knees as an after-effect of being severely burned and who reported that he definitely felt uncomfortable in intimate situations: “You have to get into explaining it. People ridicule people with disabilities so you tend to not open up with people because you want to avoid hearing it.” (Williamson & Walters, 1996, p. 228)

Since bodily awareness forms such an integral part of human functioning, the amputation patient experiences a disruption in aspects of self seemingly unrelated to the physical function of the amputated limb, such as emotional stability and sexual functioning. How the person then reacts to these unexpected changes depends on his/her functioning and coping mechanisms prior to the amputation as well as the larger system within which he/she functions.
2.5 The impact of amputation

All of the aspects examined here are interrelated. It is likely that someone whose sense of self depended greatly on his/her body image will have greater difficulty adjusting to the change. A person who had difficulty with emotional trauma prior to the amputation is likely to have greater difficulty in that area, etc.

Family systems and society as a whole place great emphasis on a person’s role within these systems. This role is threatened by amputation because the amputee might not be able to function physically as before. It is also greatly influenced by people’s attitudes toward physical appearance in the ecology of the amputee. Unfortunately the unsettling feedback the individual is likely to receive from his/her ecology has a reinforcing effect – inescapable because of the recursive nature of systems. This then results in even lower feelings of self worth and greater damage to the positive experience of self. The amputee is likely to exhibit feelings of depression and loss of self worth, this in turn results in the ecology showing greater rejection. Thus a self-perpetuating spiral forms that pushes the amputee into greater despair.

The main psychological risks seem to be related to anxiety and mood. It is postulated here that should these aspects be addressed, for example through the use of guided imagery, the amputation patients’ experience of self may not alter as dramatically as seems to be depicted in the literature. Amputation patients are then likely to present a much healthier image to their ecology which in turn could become more accepting and
may reflect less depressive feedback toward the amputee resulting in a system where significant change can occur.

Fig 4.1 depicts the rehabilitation ecology of the amputation patient, attempting to show the relatedness between the experience of amputation, the person’s individual characteristics and the ecology. The experience of amputation is influenced by many factors related to the degree of trauma to the patient as well as the physical and psychological factors that can come into play after amputation. In addition, the context of pre-morbid personality functioning and meaning created from the amputation influence the amputee’s adaptation in his/her recovery environment where caregivers (both professional and non-professional) and societal attitudes calibrate this adaptation.

2.6 Conclusion

From the accounts of the main identified psychological and physical experiences related to amputation a picture emerges. The amputee seems to be a person in extreme crisis, accosted by physical demands, adjustment, discomfort and pain from all sides, needing to make the mental leap to incorporate a whole new experience of his/her own body into his/her sense of self. This coincides with various emotional and mental stressors that are mostly dealt with as disorders in their own right – depression, severe anxiety, PTSD. There seems to be more of everything present in the amputee’s ecology. More pain, more adjustment, more disruption, more permanent change than is present in most other systems in crisis. In addition, a greater need for support and assistance is implied, which
unfortunately seems lacking if one looks at the self-isolation that often accompanies this event.

The next chapter presents a literature review of the concept of guided imagery as well as research conducted into various ways that it may be applied in various medical and psychological contexts.
Fig 4.1 The amputation patient’s ecology related to the impact of amputation:

**Individual characteristics**
- Pre-morbid personality
- Pre-morbid sense of self
- Coping strategies
- Meanings attached to events/traumas

**Experience**
- Degree of:
  - trauma
  - loss
  - pain
  - discomfort
- As seen in:
  - body image change
  - anxiety
  - depression
  - PTSD
  - phantom limb sensations
  - shock
  - dissociation
  - sexual functioning

**Amputation patient**

**Recovery environment**
- Social support network
- Caregivers
- Cultural characteristics
- Societal attitudes

**Adaptation**
- Acceptance and growth vs Depressive mood and damaged sense of self
Chapter 3 – Guided imagery

“We are what we think. All that we are arises with our thoughts. With our thoughts, we make the world.”

-Buddha

3.1 Introduction

In Chapters 2 and 4 the life-world of the amputation patient as well as the rehabilitation process are explored. Some of the main aspects of concern that emerge are anxiety and mood symptoms of the amputee as well as a concern by the medical staff that the amputee is not adequately prepared to go through the process of amputation. In addition, the pain and discomfort, the enormous adaptation to life and change in experience of self are aspects that seem to be inadequately addressed during the rehabilitation process.

This chapter explores a possible way with which these aspects could be addressed. The uses of guided imagery, specifically in the medical field, is presented and proposed as an effective method of providing assistance and relief to amputation patients.
3.2 What is guided imagery?

Guided imagery is a technique that has been in use for centuries. As a healing tool, Navajo Indians were known to practise elaborate forms of imagery which encouraged the patient to see him/herself as healthy. There is also evidence that ancient Egyptians and Greeks, including Archimedes and Hippocrates believed that images released spirits in the brain that could, if the image were strong enough, cause the body to manifest these symptoms (Naparstek, date unknown).

Guided imagery can be seen as the process of using words (narration) and often music, to take the listener into an inner journey, for a particular purpose (Naparstek, date unknown). Since many responses in the body do not distinguish between physical experience and the person imagining having that experience, this technique can be seen as highly adaptive and may be used across a broad spectrum.

Imagine the experience of getting caught up in a scary movie. The adrenaline that starts to surge when you can seen the serial killer stalking his next victim - the increase in your heart rate just as the killer pounces. This imagined experience can produce the same physical response than if you were faced with a real life threatening situation. In the same way, the mental image of relaxing
peacefully beside a waterfall in a beautiful forest setting can be used to attain a level of inner tranquillity.

Imagery can be seen as the most fundamental language we have. When we recall events from our past or childhood, we think of pictures, images, sounds, pain, etc. The recollections are hardly ever shaped through words but remain images in our minds that can be entered into almost at will.

Images aren't necessarily limited to visual content but can also include sounds, tastes, smells or a combination of sensations. A certain smell, for example, may invoke either pleasant or unpleasant memories. Similarly, going to a place where you had a bad accident may instantly invoke visions of the accident and initiate flight or fight response.

Think, for example, of holding a fresh, juicy lemon in your hand. Perhaps you can feel its texture or see the vividness of its yellow skin. As you slice it open, you see the juice squirt out of it. The lemon's tart aroma is overwhelming. Finally, you stick it in your mouth, suck on it and taste the sour flavour as the juices roll over your tongue.

More than likely, your body reacted in some way to that image. For example, you may have begun to salivate.
Imagery can be seen as the biological connection between the mind and body which can be extremely useful in mind body healing. Guided imagery is thus seen as a mental imagery technique that allows the therapist to guide the subject through certain pathways toward a specific goal. According to Leuner (1983), this allows for in an inner experience that results in a fundamental self-confrontation. The potential to release affective impulses through this process gives rise to the possibility of synthesising something new into the personality, even though fantasy is utilised.

3.3 Benefits of guided imagery

Research has shown that guided imagery may be beneficial in a variety of settings and for a variety of outcomes. Some of these are mentioned below:

- **Reduced stress and anxiety**
  In studies conducted by Tusek, Cwynar and Cosgrove (1999), and Tusek, Church and Fazio (1977), it was found that the use of guided imagery significantly decreased levels of stress and anxiety in patients undergoing surgery.

- **Decreased pain**
  Studies conducted by Tusek, Church, Strong, Grass and Fazio (1997) and Tusek, Cwynar and Cosgrove (1999) showed positive uses of guided imagery in the control of pain. Patients showed a significant decrease in pain and anxiety, reducing narcotic
consumption and in some cases being able to leave hospital days sooner that patients not exposed to guided imagery tapes.

- **Decreased side effects**

Tusek (1999) and Tusek et al. (1997) have found that the use of guided imagery tapes can significantly reduce the side effects of treatments and strengthen immune functioning of patients that undergo invasive surgery.

### 3.4 Applications of guided imagery

In addition to the above benefits, a number of studies have been conducted on the use of guided imagery on specific medical conditions. A summary of these studies is given below.

- **Headache**

Initial research suggests that guided imagery may provide added benefits when used at the same time as standard medical care for migraine or tension headache. Some studies show that relaxation therapies, including use of guided imagery, may be as effective or more effective in reducing the frequency of migraine headaches than are modest doses of a beta-blockade medication (Baumann, 2002; Mannix, Chandurkar & Rybicki, 1999).
• **Cancer**
Some studies suggest that guided imagery techniques (such as relaxation and imagery training tapes) may improve quality of life and sense of comfort (mood, depression) in cancer patients (Kwekkeboom, Kneip & Pearson, 2003; Hosaka, Sugiyama & Tokuda, 2000).

• **HIV**
Initial evidence suggests that occasional use of guided imagery techniques may improve quality of life in people with HIV (Gruzelier, 2002).

• **Anxiety and wound healing after surgery**
Initial evidence suggests that guided imagery relaxation audiotapes may reduce postoperative anxiety, improve healing and relieve stress (Holden-Lund, 1988).

• **Anxiety and depression in multiple sclerosis**
There is early research that the use of imagery may reduce anxiety but not depression or physical symptoms in patients with multiple sclerosis (Maguire, 1996).
• **Memory**

Preliminary research suggests that guided imagery of short duration may improve working memory performance (Hudetz, Hudetz & Klayman, 2000; Hudetz, Hudetz & Reddy, 2004).

• **Fibromyalgia**

Initial research suggests possible reductions in pain and improvements in functioning (Walco & Ilowite, 1992).

• **Upper respiratory tract infections**

Preliminary research in children suggests that stress management and relaxation with guided imagery may reduce the duration of symptoms due to upper respiratory tract infections (Hewson-Bower & Drummond, 2001).

• **Insomnia**

Preliminary research supports the value of combined drug therapy and relaxation training in the treatment of insomnia (Rosen, Lewin & Goldberg, 2000).

• **Juvenile rheumatoid arthritis**

Cognitive-behavioural interventions for pain may be an effective adjunct to standard pharmacologic interventions for pain in patients with juvenile rheumatoid arthritis (Walco, Varni & Ilowite, 1992).
• Pain

Significantly lower postoperative pain ratings and shorter hospital stays in children, less abdominal pain and less pain from laparoscopic surgery have been associated with guided imagery practice. Preliminary research also suggests guided imagery may help in reducing cancer pain (Lambert, 1996; Moore & Spiegel, 2000; Sloman, 1995; Stevensen, 1995).

It is evident that many benefits are to be found when guided imagery is utilised in conjunction with more traditional medical practises which has the effect of enhancing the overall patient experience and promoting accelerated healing in many instances.

3.5 Conclusion

The next chapter investigates some aspects of two existing rehabilitation programmes from the point of view of some of the health care professionals who are involved in the programmes. Specific emphasis is placed on examining the view on additional psychological input into these programmes as well as elements the professionals feel are lacking.
Chapter 4 – The health care perspective: research design and results

The empires of the future are the empires of the mind.
-Sir Winston Churchill

4.1 Introduction

In order to obtain a sample view of current practices in South African rehabilitation programmes, a convenience sample of health care professionals within the field of amputee rehabilitation was approached. The professionals were asked to complete a semi-structured questionnaire (attached as Appendix A), relating to current practices as well as their opinions on the value of increased psychological focus in a rehabilitation programme. As with the self-reports of an amputation patient presented in Chapter 2, the reports of the health care professionals are considered as their ‘truth’ and will be used during the compilation of the rehabilitation programme offered later in this study.

The purpose of this particular study is focused on the understanding of the experience of amputation and the broader ecology of the amputee. To establish this, a number of sources have been consulted: self-reports of amputees, health workers in the field as well as a literature review of previous studies and as such a 360 degree view of this context has been sought to increase the quality of the study.

4.2 Research design

Use was made of semi-structured questionnaires completed by professionals involved in the rehabilitation process of amputation patients at two state institutions in Gauteng, South Africa. Practitioners in the field are asked for their input on a number of aspects, informed by the research presented in Chapter 2. This was done in order to ascertain their
views on current practices as well as their opinions on the value of increased psychological focus in a rehabilitation programme. Themes were then extracted during the reading of these questionnaires, informed by the aspects highlighted in the experience of amputation (Chapter 2). These themes will then be used during the development of a suggested rehabilitation programme with the aim of developing a programme that may be more effective than some currently in use.

4.2.1 Qualitative research:

Qualitative research uses a naturalistic approach that seeks to understand phenomena in context-specific settings, such as "real world setting (where) the researcher does not attempt to manipulate the phenomenon of interest" (Patton, 2002, p. 39). Qualitative research, broadly defined, means "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (Strauss & Corbin, 1990, p. 17).

a) Reliability and validity in qualitative research

Although the term ‘Reliability’ is a concept used for testing or evaluating quantitative research, reliability is important for all types of research. If we see the idea of testing as a way of eliciting information then the most important test of any qualitative study is its quality (Golafshani, 2003). A good qualitative study can help us “understand a situation that would otherwise be enigmatic or confusing” (Eisner, 1991, p. 58). The reliability and validity of a qualitative study can be said to depend on the study’s ability to explain a concept not known prior to the study as well as contribute to the generation of understanding of the concept (Stenbacka, 2001, p. 551).

In searching for the meaning of validity in research, Davies and Dodd (2002) find that the term ‘rigor in research’ appears in reference to the discussion about reliability and
validity. Davies and Dodd (2002) argue that the application of the notion of validity in qualitative research should differ from that in quantitative research by “accepting that there is a quantitative bias in the concept of rigor, we now move on to develop our reconception of rigor by exploring subjectivity, reflexivity, and the social interaction of interviewing” (p. 281).

As synonymous with the traditional concepts of reliability and validity in qualitative research, Pulkkinen (2003) suggests that evaluating trustworthiness of qualitative research may be employed when the more traditional measures are not applicable due to the nature of the research conducted. By trustworthiness, he refers to the credibility and validity of the qualitative research as assessed externally or from the perspective of the analysis itself. Pulkkinen (2003) suggests that the analysis of themes should be evaluated for the influence of the researcher and that descriptive (factual accuracy), interpretive (as influenced by the viewpoint of participants) and theoretical (the degree to which the research matched with the theory) validity may add to the trustworthiness of research.

These notions are certainly consistent with the post-modern, systemic view taken within this study and as such the traditional concepts of reliability and validity found in quantitative research are found to be more fluid within the qualitative paradigm, allowing the researcher greater flexibility and the reader greater scope of evaluation. In addition, due to the self-report nature of the information gathering phase, trustworthiness related to the interpretation of the meaning of statements supplied does not come into question as very little interpretive input has been added by the researcher.

4.2.2 Semi-structured questionnaires

Semi-structured questionnaires (Appendix A) were chosen for this study as this method provided the most convenient way for the medical and support staff who were respondents in the study to respond. As with all qualitative research, the goal was to
access the perspective of the people involved and the assumption was made that this perspective would be meaningful and knowable through questioning (Patton, 2002).

The questionnaires consisted mainly of opinion or value questions, where the respondents were asked to give their interpretation of the rehabilitation process as well as their opinions of possible improvement of this process. Some experience and demographic questions were included to obtain a view of the background of the health care workers and the extent of their involvement in the rehabilitation process. In addition to these, the emotional responses of the respondents were gauged with regard to their feelings of adequacy in their emotional repertoire with the amputees they work with.

4.2.3 Ethical considerations

Interviews and questionnaires can often be viewed as interventions in their own right. They lay open thoughts and feelings, knowledge and experience within an interviewee that can leave him/her profoundly affected (Patton, 2002). It is with this in mind that the questionnaire or interview should be constructed with care and consideration for the ethical implications it may have.

Patton (2002) identifies some key ethical aspects that a researcher needs to take into account when embarking upon the research journey:

a) Promises and reciprocity

With promises and reciprocity, it is important to consider what the respondents get out of the research in which they participate. Promises should not be made lightly as the researcher would be held by them and cannot ethically damage the trust of the respondent. It was therefore important to consider the value of the research being conducted. The research findings will be made available to the health care professionals who participated in this study in the form of a proposed rehabilitation programme that they may choose to adopt into current practises or draw from in some ways.
b) Risk assessment

When assessing the risk involved in disclosure of information during an interview or in a questionnaire, Patton (2002) points out the importance of considering whether the respondents will be exposed to psychological stress, whether there are legal liabilities or political repercussions to consider and whether the participants could expose themselves to ostracism by peers or others for having talked.

During the study conducted, no such risks were indicated. Some questions with regard to how adequate the respondents feel with regard to their emotional resources in working with amputees may have led to a degree of psychological stress. It is with this in mind that the question was stated in a non-probing manner and no other questions of this nature were included in the questionnaire as the researcher was not available on hand during completion of the questionnaires to attempt to contain any discomfort that may have arisen. The respondents were, however, provided with contact details should they have felt the need to offer more information or contact the researcher personally.

c) Confidentiality

In most studies, issues of confidentiality are paramount and reasonable promises of confidentiality made by the researcher need to be fully honoured (Babbie, 1992). In the study conducted, respondents were not asked for any identifying information, save their occupations. The findings are not reported based on the two rehabilitation programmes investigated, but as a joint overview in order to protect the confidentiality of the respondents.

d) Informed consent

Patton (2002) urges that the researcher determines what kind of informed consent is necessary for mutual protection of the researcher and the respondents. Since the research conducted was in the form of a questionnaire, the respondents were able to determine the
nature of the questions prior to agreeing to submit their answers. The respondents were also informed of the nature of the study and the proposed use of the information they provided.

e) Data access and ownership

Cicourel (1964) and Patton (2002) both advise determining who will have access to the collected data as well as who owns this data prior to the study. As previously stated, the participants in this study will be able to review the programme to which their input contributed. Since this study has been conducted as part of the fulfilment of a Masters degree, the publication thereof remains at the discretion of the university. The intellectual property of the processed information remains that of the researcher.

f) Interviewer mental health

It is important to determine what the field researchers will be exposed to during a study and what possible debriefing and processing may be merited (Patton, 2002). The scope of the study conducted does not require this consideration.

g) Advice

Patton (2002) lastly suggests that the researcher has a confidante and counsellor during the process of research as not all matters of ethics can be anticipated beforehand.

4.3 The interviewees

The health care professionals work in rehabilitation of amputees at two different state hospitals in the Pretoria, Gauteng area namely Pretoria Academic Hospital and One Military Hospital. The professionals involved are reported on below. The number of respondents in a given profession that participated is given in brackets after their occupation. It also seems useful broadly, to divide the health care workers into two categories, namely medical staff – who work with the patient on a largely physical basis,
and supportive personnel – who support the patient and the family during the adaptation process and who also support the medical staff with regard to reports on the patient’s overall recovery. In the case of some professions, the medical and supportive functions become blurred as the health care workers spend a great deal of time physically preparing the patient but also need to keep them motivated to sustain them through the process. These are reported as hybrid medical-supportive staff. At no time is one health care worker’s role considered as more or less vital than that of another.

4.3.1 Medical staff

a) Orthopaedic surgeon (1 respondent)

The surgeon is usually the leader of the rehabilitation team, monitoring patient progress and often performing the amputations as well. The orthopaedic surgeon that formed part of this study has been involved in the field of amputation rehabilitation for 12 years.

b) Orthotist/Prosthetist (3 respondents)

They reported respective involvement in rehabilitation for four, six and eight years. The role of the orthotist/prosthetist in the rehabilitation process is to evaluate the condition of the amputation after the operation. The patient is taught how to take care of the wound and start to cone it (bandage it correctly so that it is shaped properly for the prosthesis to be fitted). The orthotist/prosthetist would then take measurements for the prosthesis and cast, manufacture and fit the prosthesis. In some instances the orthotist/prosthetist would also get involved in starting to help the patient use the prosthesis.
4.3.2 Hybrid medical-supportive staff

a) Physiotherapist (1 respondent)

The physiotherapist is usually involved in all stages of rehabilitation. He/she starts to work with the patient immediately after amputation on strengthening of the required muscles. He/she also gets involved in the process of coning which is followed by fitting of the prosthesis where the physiotherapist assists the patient in working on his/her balance, muscle strength, retraining of walking and desensitisation of the stump. In cases where a prosthesis is not available or recommended, the physiotherapist will assist the patient in the use of a wheelchair or crutches. The person involved in this study had been working with amputees for approximately one year.

b) Biokineticist (1 respondent)

The biokineticist who responded to the study had been involved in the rehabilitation of amputees for three years. The biokineticist’s role is closely linked to that of the physiotherapist in the sense that he/she is largely involved in the strengthening of various muscle groups that the patient will need to depend on.

c) Occupational Therapist (1 respondent)

The occupational therapist is sometimes involved in the pre-amputation stages where information is given to the patient about possible expectations as well as on the process of rehabilitation after the surgery. Post-surgery, the occupational therapist works with the physiotherapist during the process of coning and desensitisation of the stump. He/she also gets involved in the practicalities of obtaining a prosthesis / wheelchair / crutches for the patient and conducts home visits if necessary to advice the patient and his/her family on how to adapt the home environment for the amputee. The occupational therapist who
responded to this study had been involved in the rehabilitation team for approximately two years at the time the questionnaires were completed.

d) Nurse (1 respondent)

The nurses involved in the rehabilitation ward give pre- and post-operative care and information to patients and their families. They are the ones that take care of the patients on a daily basis and ‘fill in the gaps’ when the other health care professionals are not scheduled to do anything specific with the amputees. The nurse involved in this study had been working in the rehabilitation ward for five years.

4.3.3 Supportive staff

a) Social worker (1 respondent)

The social worker who agreed to participate in this study had been working with amputees for eight years. The social worker’s role involves pre- and post-operative counselling and the provision of information to the patients and their families. The social worker is also responsible for follow-up with patients who have to attend the rehabilitation clinic regularly after the surgery.

b) Psychologist (2 respondents)

The two psychologists that responded to the questionnaire had both been involved with the amputation patients for less than a year. They work closely with the social worker in that they are involved in pre- and post-operative counselling. They work with the amputation patient to ensure that he/she is emotionally receptive to the amputation process and give regular feedback to the multi-disciplinary team with regard to the progress of the patient’s recovery.
The respondents provided a broad overview of the rehabilitation process from their differing perspectives. Questionnaires were returned by at least one of each profession involved in the multi-disciplinary rehabilitation team, providing quite a comprehensive overall report of the process covering all angles from which the patient is approached.

### 4.4 The questionnaire

The questionnaire which the health care professionals were asked to complete, asked questions regarding the professionals’ involvement in the field of rehabilitation as well as regarding their specific roles within the multi-disciplinary team. Respondents were further asked about their views on the success of current rehabilitation practises and their observations of the amputees’ psychological and emotional well-being during the rehabilitation process. Respondents were also asked about their experience of the amputation patients’ family involvement to add to the overall understanding of the process to which the amputees are subjected.

In order to obtain a view on possible shortcomings within the programmes, respondents were asked about their opinions on the adequacy of information provided to amputees as well as their opinions on additional psychological input for amputees during the rehabilitation process. Lastly, respondents were asked about their own feelings of inadequacy with regard to supporting amputees on an emotional level. Space was also allocated for recommendations toward improving the rehabilitation programmes that the health care professionals are involved in. A copy of the questionnaire is provided in Appendix A.

### 4.5 Themes extracted

The questionnaires were evaluated by the author for themes informed by the research presented in Chapter 2 on the experience as well as the process of rehabilitation after amputation. Due to the systemic focus of the study, the family system of the amputee is
included and information was elicited from the health workers on this topic as well. In addition, due to their experience in the field, the questionnaires also aimed to elicit additional input from the respondents that may only be available to those working with amputation rehabilitation on an ongoing basis. The following themes were therefore identified and are expanded on as the results of the research conducted:

- The state of the amputee
- Extent of family support
- Need for more psychological involvement
- Recommendations made by health care professionals

The following information was obtained with regard to the above mentioned themes:

4.5 1 The state of the amputee

The respondents seem to agree that the physical recovery of the amputee is often very good and great success is achieved with this aspect of the rehabilitation. A lack of funds was often cited as a shortcoming toward providing better equipment and service for the amputees. It is interesting to note that the professionals mostly involved with the amputees in a post-operative capacity and on a more practical level (notably orthotist/prosthetists and the orthopaedic surgeon) considered the patients to be inadequately informed of the effects and implications of amputation, especially prior to the surgery. Some of the professionals involved throughout the entire process and responsible for some of the psychological support found the level of information provided to be adequate.

On an emotional level, reports of depressive mood, emotional lability as well as negative thoughts and perceptions were reported to be observed often amongst amputees. The depressed mood and anxiety seem to be more prevalent during the early stages of the process of amputation rehabilitation. Some health care workers attribute this to patients not knowing what to expect and they attribute the improvement in mood and anxiety to
the patients gaining more confidence. These mood symptoms also seem to be consistent with the information presented in Chapter 2 on the amputee’s experience of amputation.

4.5.2 Extent of family support

The health care professionals reported that in most cases and wherever possible, the amputee’s family members and significant others are involved during the process. They are mostly reported as being very supportive and when they are involved, they seem to support the patient all the way.

4.5.3 Need for more psychological support

On the question of whether the amputees might benefit from more efforts to improve their psychological well-being, nine of the eleven respondents answered in the positive. One, the social worker, remained undecided but stated that support groups before and after amputation might be useful. One other, one of the psychologists, was of the opinion that the level of psychological support currently provided was sufficient.

4.5.4 Recommendations made by health care professionals

Surprisingly, only three main recommendations were offered by the various health care professionals. Most prevalent amongst the recommendations offered was the need for more funding. According to the professionals, more funding would also shorten the waiting period for prostheses and provide amputees with better employment opportunities to sustain themselves. Secondly, many respondents would like to see patients better informed of the process of amputation and the rehabilitation that follows. Linked with this, the need not to create false hope was mentioned as an important criterion. Lastly, many respondents mentioned a need for more psychologist and social work involvement with the amputees in hospital as well as more trained health care workers in their communities.
4.6 Discussion

Consistent with the literature (Desmond & MacLachlan, 2002; Grise, Gauthier-Gagnon & Martineau, 1993), a large majority of the health care workers approached have become aware of a lack of focus on the psychological well-being of the amputees in amputation rehabilitation programmes. Many of them reported that they sometimes feel overwhelmed and inadequate in providing emotional support to the amputees. Considering the anxiety and depressed mood often found among amputees, this makes the work of the rehabilitation team that much harder and the risk is that rehabilitation team and amputees could develop a dynamic where they could almost ‘feed’ off the inadequate feelings of each other, providing a very unsafe and damaging environment for recovery.

The lack of adequate information, cited predominantly by the medical staff, raises more concerns. Are the medical staff in a better position to judge the extent of the amputee’s education about the process? Do the multi-disciplinary team communicate well enough to provide such feedback to one another? Are the support staff adequately informed so that they may pass on this information to the patients, or are they unaware of their own shortcomings? It is also possible that both medical and supportive staff provide the best care and education they are able to, but that the amputees are too anxious to concentrate and retain any of the information provided.

The question of more funding would need to be addressed on a macro level. Considering the lack of information the South African health care services have with regard to the state and nature of amputation performed within South Africa, it is not likely that the funding situation will be addressed very soon. This creates a challenge to save funds and optimise available resources so that they may be better allocated. Funds may be saved when available staff provide correct information, guiding the amputee through the process more effectively. This is likely to have an impact on the anxiety of the patient.
and if, in addition, mood symptoms are addressed, the need for subsidised medication and repeat follow-ups with the patient could be reduced.

4.7 Conclusion

In the following chapter, a modified rehabilitation programme is suggested which incorporates the use of guided imagery in the rehabilitation of amputation patients. Examples of guided imagery exercises are also incorporated in this chapter.
Chapter 5 – Rehabilitation programme for amputees

5.1 Introduction

As has been referred to in previous chapters, the focus placed on the psychological wellbeing of amputation patients in current traditional medical rehabilitation programmes is minimal. This investigation also makes reference to a number of medical and para-medical professionals who all agree that additional psychological support for not only the amputees but the caregivers themselves would possibly be of great value in future programmes.

In this chapter, a modified structure to traditional amputee rehabilitation programmes is suggested incorporating some aspects of guided imagery, specifically targeted on the experience of self of the amputee and possible methods to enhance and bolster this as a positive experience. As seen in Chapter 4, the experience of the amputee is often accompanied by severe anxiety, extreme pain, physical discomfort and depression. In addition, there remains the forbidding challenge of adjusting to a whole new body-image which, in many cases poses the greatest threat to the experience of self of the amputee.

The proposed rehabilitation programme is structured in such a manner that the majority of healthcare professionals who at one time or another have contact with the amputation patient can and should be included. This is not a
programme currently in existence and was designed by the author, informed by
the research presented in Chapters 2, 3 and 4. In order to include the family
system of the amputee, the programme structure also require these individuals to
participate, thus forming an active component of the rehabilitation and future
recovery of the amputee. The intention is for any healthcare professional to be
able to run the programme – this would include nurses, occupational therapists,
physiotherapists or psychologists. The programme has been designed in such a
way that any health worker can facilitate it – in light of the resource scarcity
highlighted through the research conducted. The medical rehabilitation team are
required in specific segments but their time is freed up but not needing to attend
all sessions of the programme

In addition to the very essential medical and practical information supplied
through the programme, components of guided imagery are included to re-
enforce the bolstering effect of the process

What follows is the proposed structure of an 8 week long rehabilitation
programme, with a 90 minute meeting per week. Reference is made to the input
required from occupational health as well as physiotherapy with the content
supplied only for the general flow of the programme as well as suggested guided
imagery that could be utilised. Any medical information required to be
distributed to the groups have not been included as this kind of information falls
outside the scope of this study. The majority of rehabilitation programmes in
place would already have material of a practical as well as medical nature available and alterations to these may not be required.

### 5.2 General organisational aspects

It is suggested that the amputation rehabilitation groups include a minimum of 4 amputees and their relatives. The groups should not exceed 20 people to maintain an environment conducive to discussion.

A suitable meeting room should be available for these meetings with chairs arranged informally, preferably in a circle or semi-circle. Personnel required to attend the various sessions should confirm their availability on their respective dates and in addition to confirming the dates with amputation patients and their relatives, consent should be obtained from patients for relatives to participate in joint sessions.

The group facilitator should be well prepared for each session in order to promote comfort and confidence among the group members. Informational material should be handed out to both amputees and family members where relevant. It is recommended that the groups be run in conjunction with the physical rehabilitation of the amputee and the relatives that participate are either living with the patient (parents, partner, possibly children) or see the patient on a
regular basis – to this end, should no relatives be available to participate in the programme, close friends may also be invited.

Each session should begin with an open discussion of any matter related to the programme that came up during the previous week as well as a quick recapitulation of the essentials of the previous session.

5.3 Week 1

Attending: Patients and family members

Content: Introductory session.

Material: Attendance list for contact details. Name badges.

This session is aimed at introducing the content of the rest of the rehabilitation programme to patients and family members. It is suggested that patients and relatives are given the opportunity to briefly introduce themselves and if they wish, give some background on their amputation and the events leading up to it. Name badges should be provided to facilitate group members getting to know each other. It is essential that the group facilitator participate in the process and also wear a name badge.

During this session, the structure of the remainder of the programme should be discussed, listing broad topics as well as giving information on the medical and para-medical staff that will participate at various points. In addition, it is
recommended that participants be informed that guided imagery will be utilised during the programme.

5.4 Week 2

**Attending:** Patients and orthopaedic surgeon.

**Content:** Medical details regarding amputation, patients’ concerns, promoting positive experience of self

**Material:** Information booklets on upper limb amputation, lower limb amputation, brachial plexus injury as well as any other additional relevant injury / condition that may necessitate an amputation.

This session is utilised by the medical expert available to elucidate and discuss the medical nature of the various possible amputations. By separating the patients from family members, it also offers the opportunity for them to raise any personal or private concerns regarding the process and their condition. To conclude the session, the group facilitator assists the group through a guided imagery exercise aimed at promoting a constant and consistent sense of self, regardless of circumstance.

Guided imagery (to be read with a gentle, measured, slow and calming voice):

*As you sit in this room, become aware of your breathing, focus your attention just on the sound of it, get to know the rhythm of your breath.*
As you do this, you may also start to become aware of the person sitting to your right, if there is someone, as well as the person to your left, if there is someone. Although you are aware of them, your focus remains on your own breath as they seem to fade to the back of your mind.

Now, on my count, start to take a deep breath in, 1...2...3...4...5...and exhale slowly, 1...2...3...4...5..., breathe in, 1...2...3...4...5...and exhale, 1...2...3...4...5...again inhale, 1...2...you may want to close your eyes at this point and exhale, 1...2...feel free to go ahead and close your eyes. Another inhale 1...2...3...4...5...hold it there for two counts and exhale, 1...2...3...4...5...

Return to breathing normally but stay aware of the rhythm of your own breath.

As you listen to the sound of your breath, imagine yourself as you are at the moment, sitting in this room, having heard all that was discussed today and just take a moment to keep that image in your mind.

<Pause for approximately 10 seconds>

Now imagine yourself as you were yesterday. What were you doing? Who did you talk to? Where were you? What did you have for breakfast, lunch or dinner?

<Short pause>
Let’s take you even further back. Think back to your birthday last year. Was it raining, was the sun shining? How do you remember this day?

<Short pause>

Now imagine yourself ten years ago. How old were you then? Who were your friends? Where did you live? Take a moment to explore this time.

<Slightly longer pause>

Let’s go even further back to 20 years ago from now. What was your age? What were the things you thought about? What did you get up to? Where did you spend most of your time? Who did you spend most of your time with? Take some time to get re-acquainted with yourself at this time.

<Slightly longer pause>

Now let’s try something a little different. Imagine yourself ten years on into the future. Do you have children? If you do, what are they getting up to? What do you spend your time with? What are you like as a person?

Now let’s go 20 years into the future. Who are you surrounded by? Take a moment to have a look around this future life of yours.

<Slightly longer pause>
Once you’ve explored this future a little, keeping your eyes closed, return your mind to this room, to the chair your sitting on right now. Let’s take a moment to reflect on the journey that you’ve just undertaken. Whether you were in yesterday, the distant past or the distant future, there was a part of you that remained constant, a part of you that you instantly recognise as yourself. I want you to become aware of this part now. Get to know it a little better. Does it have a shape, a texture, a colour, perhaps a sound? This is you, regardless of your situation or circumstance, the essence of yourself that you have just experienced which remains constant and cannot be altered by time, space or any other circumstance.

As you now return your awareness to the room, this sense of yourself will remain and you will take it into the week ahead.

In your own time, you can open your eyes and come back into the room.

The facilitator ends by asking a few questions on how the guided imagery was experienced in the group and keeps any issues raised in mind for the remainder of the programme.

5.5 Week 3

**Attending:** Family members and orthopaedic surgeon.
Content: Medical details regarding amputation, relatives’ concerns, focus on inner resources

Material: Information booklets on upper limb amputation, lower limb amputation, brachial plexus injury as well as any other additional relevant injury/condition that may necessitate an amputation.

This session is utilised by the medical expert available to elucidate and discuss the medical nature of the various possible amputations. By separating the family members, it offers the opportunity for them to raise any personal or private concerns regarding the rehabilitation process and their role in the life of the amputee. To conclude the session, the group facilitator assists the group through a guided imagery exercise aimed at accessing inner resources of the individual.

Guided imagery:
As you sit in this room, become aware of your breathing, focus your attention just on the sound of it, get to know the rhythm of your breath.

As you do this, you may also start to become aware of the person sitting to your right, if there is someone, as well as the person to your left, if there is someone. Although you are aware of them, your focus remains on your own breath as they seem to fade to the back of your mind.
Now, on my count, start to take a deep breath in, 1...2...3...4...5...and exhale slowly, 1...2...3...4...5..., breathe in, 1...2...3...4...5...and exhale, 1...2...3...4...5...again inhale, 1...2...you may want to close your eyes at this point and exhale, 1...2...feel free to go ahead and close your eyes.

Another inhale 1...2...3...4...5...hold it there for two counts and exhale, 1...2...3...4...5...

Return to breathing normally but stay aware of the rhythm of your own breath.

As you listen to the sound of your breath, imagine yourself as you are at the moment, sitting in this room, having heard all that was discussed today and just take a moment to keep that image in your mind.

<Pause for approximately 10 seconds>

Imagine yourself walking through a cool, green, lush jungle. When you look up, you can see the tops of the trees high above where sunlight gently shines through the dark green leaves.

Underfoot, you can relish the soft tread of the moss you’re walking on and you can feel the soft caress of the ferns on the jungle floor as they softly brush against your legs.

As you walk, you start to become aware of the sound of water, faint at first but as you walk towards it, becoming slightly louder. As you walk through this cool,
green jungle toward the sound of the water, you can smell the sweet scent of flowers growing amongst the trees. You look up in amazement at the beautiful, bright coloured birds that fly high above through the lush, green canopy.

The source of the water is now sounding very near and as you walk, you reach a clearing in the forest where you come across a stream fed by a sparkling waterfall. As you look at the water falling endlessly into the flowing stream, you notice the water droplets sparkling like diamonds, sending tiny rainbows into the surrounding forest. The rainbows also splash toward you as you now stand on the very edge of the waterfall and you cup your hands to drink of the wonderfully, cool, refreshing water.

As you stand absorbing the scene, you notice fatigue draining from you, as if it’s draining into the ground, to be absorbed by the stream and carried away. You drink more of the sweet tasting water and as you feel the cool liquid flowing through your body, you become aware of a feeling of renewed energy, surging through you, slowly at first but building stronger as you watch the water falling and your fatigue drains away.

You start to realise that the water that the water is helping you to feel renewed and you know that the effect of this experience will stay with you, even as you begin to make your way back through the jungle. The soft, green moss under your feet reinforcing your sense of comfort. As the sound of the water starts to
fade, you feel safe knowing that you know how to find your way back to the waterfall again whenever you need to.

Take a moment now to fix this place into your memory and once again focus on the feeling of renewed energy that you have come away with. This feeling will stay with you even as your mind starts to return to this room and it will remain strong within you as you go into the week. Know that you can find your way back to the waterfall whenever you need to.

<Short pause>

Whenever you’re ready and in your own time, return your mind to this room and begin to open your eyes.

The facilitator ends by asking a few questions on how the guided imagery was experienced in the group and keeps any issues raised in mind for the remainder of the programme.

5.6 Week 4

Attending: Patients, family, orthotist/prosthetist and occupational therapist.

Content: Practical considerations (vol. I), relaxation

Material: Tip sheet to hand out prepared by occupational therapist.
During this session, the orthotist/prosthetist discusses coning with the group and answers questions and concerns around this aspect of rehabilitation. The occupational therapist discusses changes required to the home environment of the amputee and practical considerations around this (e.g. washing the affected hand, how to sleep, food preparation).

A guided imagery around relaxation and protection is facilitated by the group facilitator in order to address possible feelings of vulnerability that may be accessed through the session’s candid discussions around the practical implications of amputation.

Guided imagery:

_You have all experienced what we mean by guided imagery in your previous sessions. We will go on today with a different one and some of your sessions to come will also include more of these._

_I’d like you now to sit comfortably in your chairs and to try to put all other thoughts and worries from your mind for the next few minutes. Close your eyes if that makes you more comfortable and just try to still your mind. If a thought comes into your mind don’t dwell on it, just let it go and try to return to stillness._
Become aware of the feeling in your jaw. Are you clenching it or are you relaxing your jaw muscles? I want you to clench you jaw muscles now. Bite down hard and hold it there for a few seconds. Now release the muscles. Let’s do that one more time. Clench your jaw, 1...2...3...4...ok, now relax.

Now move your awareness to your forehead. Try to relax your forehead. We’re going to tighten the muscles in this area for a few seconds, frown hard, hold it, hold it and relax. Let’s repeat that now, frown really hard, 1...2...3...4...and relax.

As you sit there, imagine that there is a big bubble around you. It covers your body entirely. You can see through it and if you wish, others can see you but this bubble cannot burst or break. It will move with you as you move and you can move into and out of it as you please.

Take some time to have a good look at this bubble. What do the walls feel like? Touch them to find out. What colour are they? How do they reflect the light as you look out into the world?

You feel comfortable and safe in this bubble. Imagine moving out of it and back into it so you can see how easy it is to do. Practise this a few times and get to know the feeling of being inside your bubble. Are there any smells that are particularly familiar to you? What does it sound like in there? Can you hear the
outside world clearly or is it slightly muffled? Perhaps you even manage to filter
sound from the outside through as you choose.

Nothing can harm you inside this bubble. It is a comfortable and safe space
where you can relax and clear your mind. Nothing can come inside this bubble
with you unless you allow it.

You can imagine yourself in different situations you face everyday, at home, at
work or with friends, moving around these difference scenarios while safe and
comfortable inside your bubble. Moving out of it when you want to and getting
back in when you need to relax a little and collect your thoughts. You can even
see yourself folding up your bubble and carrying it around in your pocket or
purse to take out when you need to. Just knowing that your bubble is around
helps you to feel a little more relaxed about facing the rest of the day.

When you open your eyes in the next few seconds, keep your bubble around you
for as long as you like to. You can even go home with it still around you when
you leave this meeting.

Open you eyes and come back into the room.
5.7 Week 5

**Attending:** Patients, family, orthotist/prosthetist, occupational therapist, physiotherapist and biokineticist.

**Content:** Practical considerations (vol. II), stock take of programme.

**Material:** Tip sheet to hand out prepared by occupational therapist and team.

The orthotist/prosthetist follows up from the previous discussion around coning to clarify any issues around this matter and reinforce the technique. The occupational therapist and physiotherapist discuss aftercare and implications this has for the home environment and daily living of the amputee (e.g. personal hygiene, washing clothes, skills for personal independence). The biokineticist offers tips for exercise programmes that could be of benefit to the various types of amputation as well as information on passive movement.

The group participants are asked about their experience of the programme up to this point and are given the opportunity to share experiences and learning.

5.8 Week 6

**Attending:** Patients, family, orthotist/prosthetist and occupational therapist.

**Content:** Possible difficulties that have/may still occur, phantom limb pain, prosthesis, sense of self.
The occupational therapist discusses possible difficulties that have occurred or may still occur as a result of amputation such as how to deal with coldness in winter as well as phantom limb sensation.

The orthotist/prosthetist discusses all aspects around the possibilities and implications of prostheses.

The group facilitator presents a guided imagery to reinforce a constant and consistent sense of self for the amputees while family members are introduced to this concept for the first time.

Guided imagery:

As you sit in your chair, close your eyes and remember the last time you were really angry. Remember the situation and what happened around it. Remember how it felt and how you reacted. The situation may still be ongoing or it may have been resolved already. Just focus on yourself and how you felt at that moment.

Now, try to remember a time when you felt really frustrated about something. Remember your reaction to this situation and the feelings that went along with it. How did you feel on the inside looking out at this situation?
Once you’ve spent some time in your mind evaluating the two previous situations, we can move onto more pleasant times.

Remember the last time that you felt light-hearted. It may have been a joke shared among friends, or a touching moment you were a part of or observed. It may have been something completely different that made you feel as if you wanted to smile or laugh. Think of yourself in that situation. How did you feel, how did you react? What were your thoughts?

Take some time now to view these three different scenarios in your mind. Try to place them side by side and look at yourself during these very different times. What similarities are there? What differences are there? If you focus only on your own experience of these varying emotions, try to identify that part of yourself that remains the same. The essence of your personality and yourself that you will always recognise as being uniquely you.

This is the part of you that remains unchanged by circumstance, place or time. Regardless of what you may go through, the part that you have just identified stays with you and remains constant even as you may go through changes in live.

As you go through the rest of this week, try to remember more situations that you have been in where you can recognise your inner self and become aware of this
special part of yourself during every day interactions. You will soon notice just how constant and continuous this sense of you remains and you may find that you are able to draw some comfort from knowing this.

*In your own time, return to the room and open your eyes to close off today’s session.*

**5.9 Week 7**

**Attending:** Patients, family and occupational therapist.

**Content:** Recap of all previous sessions, share experiences.

The group facilitator with the assistance of the occupational therapist recaps all previous sessions and clarifies points raised by group members. An open discussion is then facilitated around lessons learnt and all group members are given an opportunity to share relevant experiences with the group should they wish to do so. If possible, an amputation patient who has completed the rehabilitation process may be invited to share some experiences of living with an amputation.

**5.10 Week 8**

**Attending:** Patients and family.

**Content:** Final session, discuss possible follow up required.
During this last session the group facilitator discusses possible follow ups that may be required with individuals and any member of the health professional team and questions that were raised in the previous session are answered should they not have been able to be clarified the preceding week.

The group facilitator presents a guided imagery on reinforcing a positive sense of self.

Guided imagery:

*We travelled in a few different ways with our minds during the course of the past few weeks and I hope that in some ways you will be able to take some of these travels with you in a positive way.*

*Make yourselves comfortable in your seats for this last journey together. Close your eyes and slowly calm your breathing, taking a few deeps breaths in and out before returning to normal breathing.*

*Imagine yourself sitting on a magic carpet. You can see its bright vivid colours and feel the soft texture of the fibres beneath you. In a moment, this carpet is going to start rising up from the earth and take you on a magical ride. If you want to, you can also use your bubble on this carpet to feel more comfortable.*
As you rise into the air on this magic carpet, you have nothing to be concerned about.

The carpet reaches a comfortable height and as you look down, you see a vast landscape beneath you. The carpet slowly starts to fly and you begin to recognise familiar places, people and events. You are flying over the landscape of your life. You are able to direct the carpet where you want to go so that many different areas of your life play out beneath you.

Sometimes the landscape changes and you see times in your life when things were very difficult for you and you didn’t know how you would ever overcome your situation. From this height though, you can see that those times do have a beginning and an end and that there are different places adjacent which you will eventually reach to overcome those difficult times. You watch as this unfolds before you and see how you conquer obstacles in your way. Some may look like mountains, even from up here, some may be like tangled forests but from your vantage point, you can always see a way around or out of those places.

You also see beautiful places where there were wonderful times in your life and where there will be again. Throughout all of this you can see that colourful, special part of yourself that is uniquely you prevail and remain constant. You are not changed by circumstance, hardship or despair. Nor are you any different
when things are easier and your life is filled with joy. Nothing can change your essence unless you choose to change.

I’m going to give you a little time to explore this landscape further. Travel to places long forgotten, fondly remembered and have a look at what the future holds for you as well.

<pause approx 1 minute>

I hope that everyone had an interesting journey. You can continue this at any time in the future. As your carpet starts to descend and you come back into the room, once again, hold on to that particular part of your unique self that you have come to know during these past few weeks. In your own time, return to the room and open your eyes.

Facilitator ends the session by acknowledging everyone’s contribution and participation and a closing open discussion on any comments that participants may wish to make.

5.11 Conclusion

In essence, the programme presented above has been designed about certain key aspects as informed by the research conducted:
• **Limited availability of resources**

This programme does not require a great deal of resources to be utilised and can be facilitated by any health worker, thereby limiting cost and input required from others.

• **Lack of family involvement**

The programme requires the attendance of the family or support systems of the amputee and has been designed to include these individuals in a larger part of the process of amputation.

• **Lack of knowledge**

The programme requires input from specialist in the field of amputation. The information these specialists are asked to present to the groups is not provided in detail as this was not included in the scope of the study but also as rehabilitation programmes observed by the author do not lack in material of this nature.

• **Increased psychological support**

The use of guided imagery as well as the presence of the support structure of the amputation patients is aimed at bolstering the level of psychological support.
during the process as well as to provided tools and resources for the attendees when they complete the programme.

The limitations of the study and suggestions for future research are presented in the concluding chapter, which follows.
Chapter 6 – Conclusion

It has been established through the research presented that there are many varied aspects that impact on the experience of amputation and that these aspects can have a marked impact on the amputation patient as well as on his/her extended family system.

This study has aimed to elucidate many of these aspects and suggests that interaction through rehabilitation with amputation patients could be enhanced by greater focus on psychological aspects which could be related to physical experiences as well as to the experience of the amputation patients of themselves.

Focus in the proposed rehabilitation programme is placed on emphasising the inner life of the amputees as well as promote support by their family system by including these family members in the duration of the programme. A number of varied guided imagery texts are suggested to enhance and bolster various vulnerable aspects in the system of the amputee. Most prominent of these relate to emphasising the idea that the amputee’s sense of self need not be altered by the experience of amputation and that indeed, the physical change that has occurred remains only that, and need not extend into the inner life of the person.
Due to the relative lack of information available on amputees in South Africa, a clear understanding of the scope of this condition could not be presented. Limited information around the process and experience of rehabilitation may have also impacted on the research presented.

Due to the limited scope of the research – interviews with health care workers in only the Pretoria, Gauteng region, care should be taken in applying the research results in other contexts.

It is recommended that further studies be undertaken in understanding the scope and impact of amputation within the South African context as no data on this could be found. In addition, the proposed rehabilitation programme should now be implemented and evaluated according to the impact it can make in the life system and adjustment of amputation patients. It may also be possible to include cost-benefit analysis in ongoing research on potential savings in already under-resourced health facilities should adjustment to amputation be improved through the suggested focus of the programme.

The programme, including the guided imagery suggested could also be modified for different contexts where the guided imagery texts may be effective.
Appendix A

Questionnaire: Amputation rehab

Thank you for taking the time to fill in this questionnaire. I am conducting an investigation into existing rehabilitation programs available to amputation patients with the aim of developing a program with the input of professionals involved in the field.

The information you supply will be treated with the utmost confidentiality and at no time will your position or identity be revealed in the study.

If you have any questions or would like to offer further input, please do not hesitate to contact me.

Rochelle Mountany
Intern Psychologist
Cell: 082 xxx xxxx

1. Occupation: ________________________________________________

2. Length of time involved in rehabilitation of amputees: ______________________________

3. Briefly describe the extent of your involvement as well as your role in the rehabilitation team:
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

4. What has your experience of the success of rehabilitation programs been? (i.e. percentage of patients that continue with relatively normal lives)
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

5. How do you experience the psychological and emotional well-being of the patients:
5.1 Prior to rehabilitation:
___________________________________________________________________________
___________________________________________________________________________

5.2 During rehabilitation:
___________________________________________________________________________
___________________________________________________________________________
5.3 After rehabilitation:


6. To what extent are the families of patients involved in the rehabilitation process?


7. In your opinion, are the patients informed sufficiently of the implications (physical, emotional, social, sexual, etc.) of their amputation?
   7.1 Prior to amputation:


   7.2 During rehabilitation:


8. In your opinion, could amputees benefit from more efforts to improve their psychological well-being?


9. If you answered ‘yes’ to the above question, how would this improvement have an impact on the success of their rehabilitation?


10. As a health care worker, do you sometimes feel that your resources to help patients on an emotional level are inadequate?


11. What suggestions would you offer to the improvement of the rehabilitation program you are currently part of?
References


