

**A Substantive Theory to explain the Impact of Living with a
Chronic Wound whilst receiving Conflicting or Inappropriate
Advice and Care**

A thesis submitted in fulfilment of the requirements for the degree of Master of Nursing
(Research)

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Declaration

I declare that except where due academic acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of this thesis is the result of work which has been carried out since the official commencement date of the approved research program; and, any editorial work, paid or unpaid, carried out by a third party is acknowledged

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ABSTRACT

AIM

The aim of this study was to explore and describe the impact of living with a chronic wound.

BACKGROUND

It is estimated that over 200,000 Australians have problem or chronic wounds at any one time (Australian Wound Management Association, 2008). Over the past 4 decades while there has been significant advancement in wound care, a high proportion of wounds become chronic. The economic cost of treating chronic wounds in Australia is conservatively estimated to be \$285 million annually for the treatment of pressure ulcers (Elliot et al 2008) and between \$553 and \$654 annually for the treatment of leg ulcers (Leach 2004). The human costs of chronic wounds (e.g. in terms of psychological, social and physical wellbeing), however, are incalculable.

Despite the availability of wound care resources and specialist services, there remains an inconsistency in the management of chronic wounds that impacts both on the quality of life of individuals with chronic wounds and the health care budget (Harding 2002). While there are a number of studies that explore quality of life issues associated with living with a chronic wound, the dimensions of the human cost of living with a chronic wound are not well understood. It is an important aim of this study to redress this gap in knowledge.

RESEARCH QUESTION

The research question guiding this study is: *How do individuals cope with living with a chronic wound?*

METHODS

Using a grounded theory approach, data were collected via in-depth interviews conducted with a purposive sample initially and then a theoretical sample of 20 participants (16 females and 4 males) living in regional Victoria, Australia. Participants were of Anglo-Celtic Australian backgrounds and aged between 18 and 92 years. At the time of interview, all had been living with a chronic wound for a period of time ranging from 3 months to 60 years. The types of wounds included: pressure ulcers, venous leg

ulcers, arterial leg ulcers, mixed venous and arterial leg ulcers and pyoderma gangrenosa. In keeping with the grounded theory method, data were analysed using the constant comparative method and open, axial and selective coding until theoretical saturation was achieved.

FINDINGS

This study found that individuals living with a chronic wound are receiving conflicting or inappropriate advice and care. This resulted in a substantive theory of *Weathering the Storm* being formulated on how individuals cope and live with a chronic wound when this is occurring. Linchpins to this theory are the core categories of *Struggling to Endure a Wounded Body* and *The Trajectory of Care*.

Individuals living with a chronic wound experience a life of uncertainty related to the struggle to endure a wounded body and the layers of professional care they receive. When they are provided with conflicting or inappropriate advice and treatment, inconsistencies of care and poor coordination of care, layers of unnecessary burden are added to their experience. The uncertainty and dissonance individuals are faced with, leads them to question their care, themselves and the expertise and professionalism of their treating health professionals. As a result, they experienced a loss of respect and trust for their treating health professionals and a loss of confidence in their care.

When provided with appropriate, consistent advice and care that is based on the best available evidence, participants described a feeling of relief and hope, were less confused and regained confidence in their care and trust in their treating health professionals.

CONCLUSION

Chronic wounds impose on individuals, an intense burden of physical suffering, cause major disruption to the normality of their lives, and often entail a constant personal struggle to secure appropriate care and understanding from their treating health professionals. In order to enable individuals living with chronic wounds to develop appropriate coping strategies, it is essential that health professionals: understand the burden of suffering associated with living with a chronic wound; ensure that they develop and maintain a high level of knowledge with regards to contemporary wound care practices; ensure that their clientele are provided with high quality care information that

is based on the best available evidence; ensure continuity of care; and foster quality professional-client relationships that negates the need for individuals to have to constantly question their care.

KEYWORDS

Chronic wounds; Wound management; Coping; Conflicting advice; Inappropriate care; Continuity of care; Nurses; Health professionals; Grounded Theory.

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GLOSSARY OF TERMS

Aetiology	The cause or origin of disease
Alginate [dressing]	Natural polysaccharide dressing derived from seaweed
Anaerobic	A micro organism that grows in the absence of free oxygen
Arterial ulcer	Caused by ischaemia, an ulcer resulting from impairment to the arterial system
Autolysis	The destruction of tissue or cells by action of own enzymes.
Chronic wound	A wound that does not heal or takes longer than normal to heal due to underlying conditions.
Co morbidities	The effect of other disease an individual has other than the primary disease of interest
Codeine	Narcotic analgesic
Colonised	Presence of bacteria which cause no local or systemic signs of infection
Compression	The use of bandaging or garments to reduce oedema of the tissues
Congestive cardiac failure	Clinical syndrome resulting from chronic cardiac decompression.
Composite [dressings]	Wound dressings that are comprised of layers of different types of dressing
Debride	Removal of devitalised tissue
Disengagement	The withdrawal from social action and interaction
Exudate	Accumulation of fluids in the wound. May contain serum, cellular debris, bacteria and leukocytes.
Fibroblast cells	Any cell or corpuscle from which connective tissue is developed
Film [dressing]	Adhesive, thin, transparent polyurethane film
Foam [dressing]	Polyurethane foam

GP	General Practitioner
Holistic	Philosophy of care that encompasses all aspects of the individual
Hydrocolloid [dressing]	Dressings made up of carboxymethylcellulose. Incorporate hydroactive or hydrophilic particles bound to a hydrophobic polymer
Ibuprofen	Non steroidal anti inflammatory medication
Infection	Overgrowth of micro organisms capable of tissue destruction and invasion, accompanied by local or systemic symptoms
Malodorous	Offensive smelling
Mixed venous arterial ulcer	Ulcer resulting from impairment to venous and arterial system
Morphine	Narcotic analgesic
Necrotic	Dead, vascular tissue
Necrotising fasciitis	Rare infection of deep layers of tissue than can destroy soft tissue beneath the skin
Oedema	Swelling of the tissues
Panadol, Panamax	Paracetamol; simple analgesic
Pyoderma gangrenosa	Idiopathic skin infection often associated with inflammatory disorders resulting in vasculitis
Specialist wound clinic	Service that specialises in the management of wounds. Staffed by Medical, Nursing and allied health professionals who are trained, skilled and experienced in wound management.
Tramadol	Narcotic analgesic
Vasculitis	Inflammation of the blood vessels
Venous ulcer	Ulcer resulting from impairment to the venous system
Wound	Trauma to any of the tissues of the body

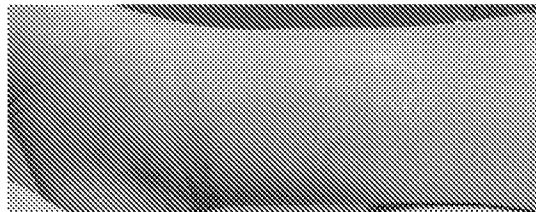
CHAPTER 1

COPING WITH CHRONIC WOUNDS

INTRODUCTION

This chapter provides an introduction to the study. To this end, attention is given first to describing the research problem and the processes informing the conceptualisation of the study. Following this, the research question guiding the study together with the study's aims and significance are outlined. Finally, a synopsis of the chapters of the thesis is presented.

Think back to a time where you scraped your knee or had a blister on your heel and you were left with a 'sore spot' or an open wound. Think about how much it hurt, the inconvenience you may have experienced for a couple of days and the fear that if you bumped or knocked the area how much it would hurt. Now imagine that you had this.....



And it turned into this.....



Now imagine having this for a month.....6 months.....2 years.....or more.

THE RESEARCH PROBLEM

It is estimated that over 200,000 Australians have problem or chronic wounds at any one time (Ellis, 2008).¹ Such wounds may take many forms, including burns, post surgical wounds and traumatic wounds, but the most prevalent chronic wounds include pressure ulcers, leg ulcers and diabetic foot ulcers (Harding 2002).

On an international scale, including Australia, the incidence and prevalence of pressure ulcers occurring in hospitalised patients has been estimated as 11% and 22% respectively (Elliot et al 2008; Graham 2003; Soldevilla 2006; Baker 2005; Strachan 2007). The prevalence of leg ulceration is estimated to be between 1 to 2% of the international population (Graham 2003; Soldevilla 2006; Baker 2005; Strachan 2007), which increases with age (Soldevilla 2006) and in Australia is estimated as 0.62 % per 1000 population, with 90% of patients with leg ulcers found to be 60 years and older (Baker 2005).

The management of chronic wounds places enormous demands on our health resources and budgets, with an estimated £1.4 billion to £2.1 billion a year being spent on treating pressure ulcers in the United Kingdom (Elliot et al 2008) and \$2.2 to 3.6 billion annually in the United States of America (Beckwith 1998). An estimated 95,695 pressure

¹ A *chronic wound* is defined as ‘any disruption of the anatomic or physiological functions of tissue, complicated by one or more chronic illnesses and lasting more than 3 months’ (Popoola 2000).

ulcers occur in Australia annually requiring a median 398,432 extra bed days, which equates to a median cost of \$285 million (Elliot et al 2008).

The cost of treating venous leg ulcers is estimated to be £300 to £400 million in the United Kingdom (Ellison 2002) and between \$553 and \$654 million annually in Australia (Leach 2004). In May 2008, the Brumby government announced a \$5 million chronic wound care plan to provide older Australians living at home or in public sector residential care facilities with improved access to specialist wound care and services (Department of Human services 2008), which will be discussed in greater detail in the literature review (Chapter 2).

On an individual level, the cost of living with a chronic wound has been identified as encompassing physical, emotional, economical and social aspects of each individual's life at varying degrees. For example there may be physical pain, reduced mobility or a reduction in social activity as a result of pain, odour and exudate. Further, the cost of dressings may cause strain on already limited incomes and there may be a reduction in overall quality of life as a result of these impacts (Spilsbury 2007; Langemo 2005; Hyde 1999).

Given the cost to the health care system in general and the costs to the individual living with a chronic wound, it is important that optimal standards of wound assessment and management are adhered to – such standards being holistic in approach - relating to the physical, emotional, economical and social aspects of each individual with a chronic wound (Harding 2002). In order to facilitate holistic wound care, health professionals must provide consistent treatment and advice that is based on the best available evidence, not only for healing to occur, but to allow the individual living with the chronic wound to

develop appropriate coping strategies (Harding 2002). The management approach should also take into account the experiential knowledge each individual with a chronic wound has with regards to wound management, as often individuals have been living with chronic wounds for many years.

BACKGROUND TO THE RESEARCH QUESTION

The treatment of wounds is as old as humankind, with the earliest recording of wound care dating back to 20,000 to 30,000 BC² (Gottrup, Leader 2004). Wound care has evolved from the ancient use of wine soaked poultices and spider webs (Dealey 2007), through to contemporary practice that incorporates the use of growth factors (Traversa 2001) and ‘spray on skin’ (Encarta 2008). Of particular interest are the historical perspectives which have the potential to influence modern wound care practice, such as the use of vinegar, which was first introduced as a wound cleansing agent by Hippocrates in the 14th century and has since been found to be toxic to the wound micro-environment (Gottrup, Leader 2004; Carville 2005). Despite this knowledge vinegar is still being prescribed today (personal observation).

The most significant advancement in wound care occurred in 1962, with the introduction of moist wound management principles by George Winter. (This will be discussed in detail in Chapter 2). Since that time, there has been much advancement, culminating in contemporary practice that encompasses holistic assessment and management of individuals with chronic wounds, rather than a practice that focuses on only the presenting wound (Harding 2002). However, despite the advances in wound assessment and management, there remains an inconsistency in the management of

² As will be discussed in Chapter 2, the earliest recording of wound care was a cave painting discovered in Spain dated 20,000-30,000 BC

chronic wounds that impacts both on the quality of life of individuals with chronic wounds and the health care budget (Harding 2002).

CONCEPTUALISATION OF THE PROJECT

The inconsistency of management refers to provision of care and advice that has little or no continuity, or is not based on the best available evidence. Examples of inconsistency of care include frequent changing of dressing regimes without justification, such as deterioration in the client's condition or their wound as a result of treatment. This practice is not only confusing to the client and detrimental to wound healing (Carville 2005), but is contrary to best available evidence, which argues that treatment regimes should be implemented for a period of two weeks in order to provide consistency of care and allow appropriate observation of the regime to ensure its effectiveness (Carville 2005). Arguably, inconsistency of care may contribute to clients experiencing possibly preventable extended wound chronicity, episodes of hospital admission and ongoing physical, social, psychological and economical limitations as a result of living with a chronic wound.

During the past 12 years I have been providing care as a clinical nurse consultant and now as a Nurse Practitioner candidate in wound management, in a multidisciplinary specialist wound clinic and have had the opportunity to make informal observations regarding the current state of play that affects individuals with chronic wounds. I have observed patients receiving inconsistent and often contradictory advice about how best to manage their chronic wounds, from treating health professionals who often have little or no formal training in wound care. In my observation, it appears to me that the main causes of the inconsistency of care results from the level of knowledge and experience of

the treating health professional, the multiplicity of services involved in the care of individuals with chronic wounds and the failure of the health professionals to listen to their clients.

When I discussed the inconsistency of care with colleagues, I developed a sense that the knowledge of many nurses, medical staff and patients, was not at a level where treatment decisions could be based on contemporary practice and the access to specialist services or expensive wound care products was limited. This was frustrating to the health professionals and patients. As a consequence, some patients sought alternative treatments such as vegemite, animal ointments or products purchased over the internet and health professionals sometimes trialled treatments based on tradition, such as the use of dry wound healing, all of which I have observed in my practice. Colleagues discussed the confusion they felt when faced with making decisions regarding wound care, partly because of their own level of knowledge and partly because of the wide range of information available to them.

When consideration is given to the availability of wound care information, it can be challenging to provide consistent care. Such information is available to access through resources provided by world leaders in wound management, such as the *Tissue Viability Society* in the UK, *The European Tissue repair society*, the *USA Wound Healing society*, the *World Union Wound Healing*, the *Australian Wound Management association*, *World of Wounds (WoW)* and less 'formal' information is also available through the internet and 'word of mouth'.

There are instances, however, whereby contemporary wound practices are not effective for a multitude of reasons. One example is the management of malignant lesions

that do not have the capacity to heal (Growcott 2000). Such instances should be seen as an exception rather than standard practice. In these cases, health professionals may be justified to resort to more ‘traditional’ remedies in order to promote patient comfort as opposed to healing,

One such example was a client I recently treated with a malignant fungating lesion overlying the carotid artery. The lesion was malodorous and often bled profusely either as a result of a minor trauma to the area such as in a dressing removal, or occurred spontaneously. Several contemporary wound practices had been trialled for this client, but were not effective in managing the odour or the bleeding. On consultation with the oncologist, the treating team and the client we decided to trial a combination of products, including tannic acid to assist in haemostasis. Little data exists that describe the use of tannic acid, although several papers had been written indicating its use in haemostasis of gunshot wounds in World War 1 (Meikle 2006). Although much of the evidence was not based on scientific research but rather on anecdotal evidence, the use of this product proved successful in increasing the quality of life for this patient by dramatically reducing the incidence of bleeding. While this is an isolated example, the success of this regime did not only occur as a result of implementation of the treatment itself, but through the leadership of knowledgeable practitioners who were using all of the information available to them and by ensuring continuity and consistency of approach following consultation with the team, that included the patient, family and treating health professionals.

MULTIPLICITY OF SERVICE

The issue of continuity and consistency of care is compounded as individuals with chronic wounds receive their care from a variety of services. Participants interviewed for this study were either self treating, with their care being overseen by their General Practitioner (GP), were attending their General Practice Clinic to have the General Practitioner or Practice Nurse treat their wounds, were receiving District Nursing Services, or a combination of all of these services. All participants at some stage in their care were referred to the specialist wound clinic in which I work, for assessment and management of their chronic wounds. Given the variety of services that provide care and advice for individuals with chronic wounds, there is a potential for inconsistencies in care and advice, unless each service is communicating clearly with the other, particularly when health professionals are at varying levels of expertise and knowledge about contemporary wound care practice. It is essential that all health professionals caring for these individuals are not only aware of current trends in wound management, but are competent in best available practice wound management (Harding 2002).

NO-ONE'S LISTENING.

Further contributing to the inconsistency of wound care received by clients, I have observed that health professionals do not always listen to their clients when it comes to managing their wounds. Many of the clients whom I have assessed and managed in the specialist wound clinic over the past 12 years, have come to the clinic with a wealth of experiential knowledge about their wounds and their management. Many of these clients have been living with chronic wounds for up to forty years and their accumulated knowledge has not always been heard by their treating health professionals.

One such example was a client I assessed several years ago who had been trialled on a new dressing product in the specialist wound clinic in which I work, only to have a local tissue reaction to that product. When the dressing was applied, the client complained of intense pain in the wound that lasted until the product was washed off. Although the side effects of the product indicated that there would be a mild stinging sensation on application, the reaction this client experienced was quite intense and specialist wound clinic staff recommended that this product should not be used for this client. The client was provided with an alternative product and written reports regarding her management, including details of the reaction to the wound product, were sent to both the treating doctor and nursing staff. As a new treatment regime had been implemented, this client was advised to attend the clinic for a review two weeks after implementation in line with the specialist wound clinic protocols, in order to ensure that the regime was appropriate. At this review there were signs of wound healing with a reduction in wound area, pain and leg oedema and the client reported feeling very satisfied with the management. As this client lived some distance from the specialist wound clinic, travelling for frequent reviews was difficult for her and she was not seen for another three months. Reports were sent to treating health professionals regarding her management with the opportunity to contact the specialist wound clinic within the three month period should they have any concerns, to arrange an earlier review or provide support with regards to ongoing management. When this client attended the specialist wound clinic for her three month review, she reported, with some distress, that the wound had deteriorated several weeks before, when a new nurse had visited. The nurse had informed the client that the wound was not healing quickly enough and changed the regime to use

the same product that had caused intense pain at the client's first specialist wound clinic appointment. The client insisted that this product not be used, but the nurse insisted that it *was* to be used and the regime was commenced. For three weeks, this client endured intense pain in the wound at each dressing change that lasted anything up to 4 hours after the dressing was applied. This situation could have been avoided had the treating nurse and subsequent nursing staff who changed the dressing, listened to their client.

As a result of similar and consistent reports I was hearing from clients attending the specialist wound clinic with regards to receiving inconsistent care and conflicting advice, I began to question how individuals with chronic wounds cope when they are not being well informed by their health professionals with regards to best practice; their wound management is inconsistent, conflicting or not based on the best available evidence; and they do not have access to specialist wound management services or resources?

This situation caused me to reflect on current practice and issues that are impacting on individuals living with chronic wounds and it occurred to me that, despite the progress that has been made in the field of wound management, as in other clinical domains, there is still a reluctance/reticence by health professionals to utilise the 'best available evidence' to inform their practice and provide consistency of care.

This study did not set out to determine the level of skill, knowledge or experience of the treating health professionals, but it became clear during the course of this study, that despite the availability of current literature, conferences, seminars, journals, the internet and wound management associations that consistent, evidence based practice is

still not being implemented by health professionals treating individuals with chronic wounds.

I am aware that rural and regional centres have significantly less opportunities for face-to-face education or mentorship and the advent of telemedicine is not always an option as a result of cost and availability. However, it remains the responsibility of health professionals treating individuals with chronic wounds to provide consistent wound care and to maintain their level of knowledge of evidence based best practice in wound management and to this end, must seek the expertise and resources available.

From my observation of the variety of services providing care for individuals with chronic wounds and the care being provided by health professionals with varying degrees of knowledge and expertise in the assessment and management of chronic wounds, I consider that there is a growing need for education and specialist services for such care. This may include specialist wound clinics, university based consultation services and medical or nursing staff who specialise in wound management, to provide support and disseminate information based on best available practice, in order that all health professionals are able to provide consistent, evidence based management for individuals with chronic wounds.

CONCEPTUALISATION OF THE RESEARCH QUESTION

The key reason I decided to first undertake this study was to develop a deeper understanding of the issues facing individuals living with chronic wounds and the coping mechanisms they developed in response, in order that I may be able to offer management that was more appropriate to their individual needs. As I observed the clients I was treating and listened to descriptions of the care they were receiving, talked to colleagues

about their wound care practices and observed the care being provided by treating health professionals, it became clearer to me that the quality and consistency of information provided to individuals with chronic wounds had a significant impact on their quality of life and ability to develop appropriate coping mechanisms. Accordingly, I resolved to investigate this problem further and to seek an explanation of how individuals cope with living with a chronic wound when their health care providers are not providing wound care and advice that is consistent and evidence based.

RESEARCH QUESTION

The research question guiding this study is: What impact does living with a chronic wound have on an individual and how do they cope?

AIMS OF STUDY

Using a grounded theory approach, the key aims of this study are twofold:

- to explore and describe the impact that a chronic wound has on the every-day lives of patients.
- to generate a theory explaining how individuals cope with living with a chronic wound.

SIGNIFICANCE OF THE STUDY

The management of chronic wounds is inconsistent and consumes a disproportionate amount of the Australian health budget (Harding 2002). It is therefore essential that health professionals who are treating individuals with chronic wounds optimise their management, not only to address issues of cost, but to make a positive contribution to the individuals' quality of life. The failure by health care providers to use the 'best available evidence' in their clinical practice and its impact on clinical outcomes

in patients is well documented and remains the subject both of research and debate in the health professional literature (Clifford, Clark 2004; Woolf 2000; McDonald 2005).

The significance of this study thus lies not in its capacity to generate new knowledge on how and why health care providers fail to take up the best available evidence in their practice, but on how *clients cope* with a poor clinical outcome (in this instance a chronic wound), which may be associated with care (in this instance, wound management) that is not consistent or evidence-based. Considering the recent announcement by the Victorian Government (2008) for funding to improve access and information with regards to wound care for older Australians, the study's significance also lies in its capacity to inform the development of an improved model of care in the management of individuals with chronic wounds that has the potential to improve clinical outcomes in this vulnerable patient/client group.

SYNOPSIS OF THESIS CHAPTERS

Chapter 1 (this chapter) provides a brief introduction to the thesis. Chapter 2, provides a review of the literature located in the context of this study, and advances a deeper discussion on the background to the study and why it is warranted. Chapter 3 has as its focus on the methodological approach chosen for this study, and the grounded theory research strategies used to advance the inquiry. The sample selected for the study, participant recruitment, and the techniques for data collection and analysis are all described. Processes used for ensuring research rigour, the ethical conduct of the research and the strengths and weaknesses of the study are also considered.

Chapter 4 has as its focus a description of the impact of living with a chronic wound within the context of the core category of *Struggling to Endure a Wounded body*.

This chapter will discuss participants' experiences within the framework of the physical events described by participants and the impact the burdens have on the every-day lives of individuals living with chronic wounds. Chapter 5, in turn, has as its focus a description of living with a chronic wound within the context of the second core category of *'The Trajectory of Care'* and discusses the impact of care on individuals living with a chronic wound, with a particular focus on the provision of conflicting and inappropriate advice and care. Finally, in Chapter 6, the substantive theory; *'Weathering the Storm of Care'* is presented. Chapter 7 presents the conclusion and recommendations made as a result of the findings of this study.

CONCLUSION

This chapter has provided an introduction to the study. First, attention was given to describing the research problem, the background to the research question and the role my experience as a Nurse Practitioner candidate played in that identifying the problem of inconsistencies of care and the processes informing the conceptualisation of the study. Following this, the research question guiding the study together with the study's aims and significance were outlined. Finally, a synopsis of the chapters constituting of the thesis was presented. The next chapter will present an outline of the literature that supports the background to this study.

CHAPTER 2

LITERATURE REVIEW

INTRODUCTION

This chapter provides a review of the literature which sets the social context of the study from the macro historical to the current context. To this end, attention is paid first to the history of wound care 1500 BC through to contemporary practice; the epidemiology and the cost of chronic wounds, in order to provide a background to the research problem. The impact of living with a chronic wound is then explored. Following this, an outline of the contemporary specialist services, resources and education available to health professionals is provided. Finally, the issues associated with evidenced based practice within the current body of knowledge are presented.

HISTORY OF WOUND CARE

The first recording of wound care was found in a cave drawing in Spain, dating back 20,000-30,000 years (Gottrup, Leader 2004). The first written recording was a surgical treatise, the Papyrus of Ebers, dating back to 1500 BC, which outlines 48 case histories of injuries. Treatments describe not only physical treatments, but also the magic spells used to cure the sick. It was believed that if someone became ill, it was caused by the wrath of God or an evil spirit entering the body (Bune, Gregor 2007). An excerpt taken from the Papyrus of Ebers is reproduced in box 2.1 and describes the treatment of a fractured skull with an open head wound using an ostrich egg and the incantation to be used during the preparation of the dressings (Bune, Gregor 2007).

Examination: If thou examinest a man having a wound in his forehead, smashing the shell of his head.
Treatment: Thou shouldst prepare for him the egg of an ostrich, trituated with grease (and) placed in the mouth of his wound. Now afterwards thou shouldst prepare for him the egg of an ostrich, trituated and made into poultices for drying up that wound. Thou shouldst apply to it a covering for physician's use; thou shouldst uncover it the third day, (and) find it knitting together the shell, the colour being like the egg of an ostrich.
That which is to be said as a charm over this recipe:
Repelled is the enemy that is in the wound!
Cast out is the evil that is in the blood,
The adversary of Horus, on every side of the mouth of Isis.
This temple does not fall down;
There is no enemy of the vessel therein.
I am under the protection of Isis;
My rescue is the son of Osiris.
Now afterwards thou shouldst cool it for him with a compress of figs, grease, and honey, cooked and cooled, and applied to it. (Bune, Gregor 2007)

Box 2.1: Instructions concerning a wound in his forehead, smashing the shell of his skull

The use of incantations in healing is described as an integral part of the treatment process in ancient Egypt and some cultures still utilise this practice in modern times (Berndt 1998). For example in traditional Australian aboriginal culture, medicine men (*magic healers*) and sorcerers (sometimes known as *kadaitcha* men) still provide care and treatment to the ill and injured (Berndt 1998). Medicine men perform a number of roles including the diagnosis and curing of illnesses through magical rituals performing of séances to connect with the spiritual world and also conducting 'inquests' into unexpected or unexplained death (Berndt 1988). Incantations are still used for a number of purposes, such as described below.

Many magic men have the power to do magic feats by singing magic songs. They can sing and cause someone to become mad. They can also sing a person's head and thus make them strong. They can sing over a spear wound, singing as they put their mouth right on the wound, thus causing it to heal up quickly. (Glass 1990.p.44)

Incantations formed an integral part of wound management in some ancient and selected contemporary practice (Berndt 1998), although the ancient Greeks based

medicine more so on empirical knowledge. They separated the supernatural from the scientific information (Price 2001) and were the first to differentiate between acute and chronic wounds, calling them ‘fresh’ and ‘non-healing’, respectively (Wikipedia 2008).

The origins of acute and chronic wound management are based on text of Hippocrates (c. 460-c. 377 BC) and Celsus (1st century AD) who helped define the beginnings of the Western medical tradition and the Egyptian *Papyrus of Ebers*, the latter detailing the use of topical wound treatments such as lint, animal grease, fresh meat and honey (Bune, Gregor 2007). The lint described was in the form of a vegetable fibre and was used to assist in wound closure, the grease was in the form of vegetable oil, snake grease, or other grease from an animal and used to form a barrier to pathogens and the honey served as an antibacterial (Bune, Gregor 2007). The meat was used as a clotting agent in the bleeding wound and it is thought that the fresh meat was used with the idea that ‘flesh heals flesh’ (Bune, Gregor 2007).

The injuries and wounds outlined in the *Papyrus of Ebers* were classified into three categories, depending on the chance of a successful treatment. There were ailments that *could be treated*, *contended* or those *that could not be treated*. An ailment that was to be contended, meant the physician had to wait and see if the patient was going to survive before starting the procedures. An example of an ailment that *could be treated* is reproduced in box 2.2, which describes an open head wound that extends to the skull.

Papyrus of Ebers Case Two:

Examination: If thou examinest a man having a [gaping] wound [in] his [head], penetrating to the bone, thou shouldst lay thy hand upon it (and) [thou shouldst palpate his wound. If thou findest his skull uninjured, not having a perforation in it.

Diagnosis: Thou shouldst say regarding [him]: "One having a gaping wound in his head. An ailment which I will treat."

Treatment: [Thou] shouldst bind fresh meat upon it the first day; thou shouldst apply for him two strips of linen, and treat afterward with grease, honey, (and) lint every day until he recovers.

Gloss: As for: "Two strips of linen," [it means] two bands of linen which one applies upon the two lips of the gaping wound in order to cause that one join to the other.

(Bune, Gregor 2007)

Box 2.2: An ailment that could be treated

It is evident from this description that the Egyptians not only had knowledge of primary wound closure (as indicated by using two bands of linen to close the gaping wound), but also the importance of antibacterial agents in wound care (as evidenced through the use of honey) (Gottrup, Leader 2004). Honey has been used for its antibacterial properties since recorded history in wound care and is still used in contemporary practice (Gottrup, Leader 2004; Stephen-Haynes 2004).

The use of wine poured over a wound as an antiseptic was also described in the Papyrus of Ebers and this practice continued through to 460-377BC, where Hippocrates promoted the use of antiseptics such as vinegar and wine for cleansing wounds and his teachings remained unchallenged for centuries (Gottrup, Leader, 2004).

Galen, who was a Greek surgeon, (130-200 AD) was the first to recognise that 'pus' exuding from wounds often heralded healing. However this was mistakenly interpreted as a positive sign of healing. It was thought that the presence of pus was necessary for a wound to heal, (known as laudable pus) and this misinterpretation was persevered well into the eighteenth century (Singhal 2006). The link between pus

formation and healing was emphasised so strongly that foreign material was often introduced into wounds to promote pus formation (Singhal 2006).

In medieval England, much of the information with regards to wound care came from the teachings of John of Mirfield (died 1407) and Thomas Morstede (c1380-1450), who categorised wounds into acute and chronic, proposing that acute wounds should be categorised into *simple wounds*, *wounds with loss of tissue*, *deep wounds*, *contusions* and *sword wounds* and is reproduced in box 2.3 (Dealey 2007).

Simple wounds: no loss of tissue, can be cured with poultices soaked in red wine, as hot as he can bear it, somewhat wrung out and applied to the spot; having first made an approximation of the lips of the wound by suturing or bandaging.

Wound with loss of tissue: concavity or concave wound; compress of fine lint soaked in egg white or a spider's web, cleansed of dust and with all parts of the spider removed as it could easily infect the whole body

Deep wound: wounds made with a knife were to be packed with a tent (pack) made from lard from salt pork or bacon wrapped around with soft cloth and introduce it to the very base of the wound. This pack was to remain in place for 3 days and then, after cleansing the wound, it was replaced with a pack soaked in a healing ointment. He recommended shortening the pack each day as the wound healed and to be aware of superficial healing. Packs were to be changed three times a day in summer, but only twice a day in winter.

Contusion: when the body has been struck and the skin and the flesh torn and rent

Sword wounds: "Wash with warm white wine and clean it out; then a poultice of hempseed may be soaked in warm white wine and squeezed in the wound...The poultice was left on the wound until it was dry. If there is need apply, lengthwise on both sides of the wound, two bolster-like plasters or close the lips of the wound so they are approximated. Then put over a plaster of clothe as before ... then linen cloth. Leave for up to 3 days. Redress, it can go as long as 7 days.

You should nothing else, but it will be cured by this method, according to Master Henry de Mondeville.

Dealey 2007.p.36

Box 2.3: Categorisation of acute wounds

Morstede's writing on chronic ulcers has been translated from medieval English into modern English and defines a chronic ulcer as a wound that took more than two or three months to heal, a definition that invariably still stands today³ (Dealey 2007, Popoola 2000). The treatment for a chronic wound is detailed in Morstede's writings and

³ A chronic wound is defined as as 'any disruption of the anatomic or physiological functions of tissue, complicated by one or more chronic illnesses and lasting more than 3 months' (Popoola 2000).

is outlined in box 2.4. Treatment proposes that the wound be *enlarged, mortified, mundified* and *fleshed*, which in contemporary terms is translated to describe wound debridement, cleansing and promotion of granulation tissue, and these practices form the basis of modern treatments (Dealey 2007).

Step 1: Enlarge the ulcer mouth. This was achieved by applying a corrosive ointment containing ferrous sulphate onto linen and laying it over the wound.

Step 2: Mortification. This seems to be the process of debridement. Debris and necrotic tissue were cleared from the ulcer either by chemical methods, such as the use of a mixture of white wine, saltpetre and copperas powder, or surgery. Surgery was particularly important if the ulcer had corrupt bone (as) it will not heal until this has been removed. Failure to remove the affected bone would delay healing, possibly by years.

Step 3: Mundification. This term means cleansing and one recipe for a cleanser included sage leaves and wormwood boiled in water and then mixed with white Gascony wine, alum and honey.

Step 4: Fleshing. In this step the production of granulation tissue was encouraged by the use of a dressing containing wax, tallow and turpentine resin, all melted together with the addition of verdigris, rose oil, frankincense powder and mastic.

Step 5: If all these steps are taken, then the ulcer will heal

Dealey 2007.p.37

Box 2.4: Treatment for chronic wounds

Mirfield and Morstede also identified the importance of treating the underlying cause of wounds, which is an integral part of contemporary practice. An example of this is the importance of compression in the use of lower limb oedema associated with chronic venous hypertension (Dealey 2007) that was first identified by Hippocrates (Gottrup, Leader 2004).

Mirfield and Morstede also identified the significance of nutrition to promote wound healing (Carville 2005), although the advice described below is not nutritionally sound, in relation to contemporary practice, it was the beginning of more holistic management, that incorporates the assessment of the whole person, rather than just the presenting wound in order to identify wound aetiology and underlying factors that are influencing the wound healing process;

Nutrition was also important and patients were to be encouraged to eat clean and wholesome food including good wine and a wide range of meat, but not vegetables (Dealey, 2007.p.36)

Mirfield also described the importance of ensuring no foreign bodies were left in the wounds, as described below, as this delays the healing process and increases the risk of infection and is a concept that continues to be taught in modern wound management practice (Dealey 2007; Carville 2005).

no hair or ointment or oil or anything fall inside the lips of the wound as their agglutination will be retarded (Dealey 2007.p.36)

Advances in wound management were made throughout the Middle Ages and the Renaissance, with the most significant advances occurring in the 19th century, with the realisation of the importance of antisepsis (Gottrup & Leader 2004). Ignaz Semmelweis, a Hungarian obstetrician discovered that if hands were washed with chloride of lime between performing a post-mortem and delivering a baby, the maternal mortality was reduced (Gottrup and Leader 2004). By introducing hand washing as a standard practice, the mortality rate fell from over 10% to 1% in two years (Gottrup & Leader 2004). Joseph Lister (Professor of Surgery, London, 1827-1912) and Louis Pasteur (French bacteriologist, 1822-1895) further revolutionised the management of wound infection recognising that antisepsis could prevent infection (Singhal 2006). Lister introduced the application of carbolic acid (phenol) in dressings to open fractures to sterilise the area and in doing so prevented wound sepsis and therefore the need for amputation. He also began to use carbolic acid spray in the operating room to reduce contamination from air borne bacteria (Singhal 2006). While wound care was advancing, with the introduction of antisepsis, so too was the development of wound dressings. Based on Lister's concept of

using dressings impregnated with carbolic acid, Johnson and Johnson developed a dressing using gauze impregnated with iodine, a version of which is still available today (Wikipedia 2008).

From the late 1800s to early 1900s, much of the focus in wound care was on infection prevention and asepsis until 1914, with the outbreak of war (Gottrup, Leader 2004). World War I was the impetus in the advancement of wound care as new types of wounds, such as bullet or shrapnel wounds contaminated with mud, required treatment and wound debridement and delayed wound closure were at the forefront of wound healing techniques (Gottrup & Leader 2004).

The most significant piece of research in wound management is attributed to George Winter who, in 1962, reported that wounds made on the backs of pigs healed quicker than when allowed to form a scab (Winter 1962). Winter formed multiple, partial thickness wounds on the backs of pigs and left half open to the air and covered the other half with a polymer film to keep them hydrated. The covered wounds healed faster, as measured by the migration of new epithelium on the wound bed. Epithelisation of the wound was retarded by the dry scab that normally covers a superficial wound and Winter found by using the polymer film to cover the wound and keep the area moist, epithelialisation was markedly increased. (Winter 1962) These findings, which were later repeated in human volunteers, now form the basis for *moist wound management principles* of the 21st century (Carville 2005). The principles of moist wound management are based on the premise that cells need moisture to grow, divide and migrate across the wound bed to optimise the formation of new tissue (Carville 2005). Using moist wound healing, there is a reduction in cell dehydration and death, increased

angiogenesis, enhanced autolytic debridement, increased re-epithelialisation a reduction in bacterial burden and infection rate, reduced pain associated with the implementation of moist wound healing principles (Keast 2008).

The principles of moist wound management have been developed over the past four decades to a point where all products used in the management of chronic wounds have been based on these principles.

The 1970s and 1980s represented the dawn of modern wound care treatment, with the development of dressings that promoted moist wound principles, such as polyurethane film and hydrocolloid dressings that are composed of a mixture of adhesive, absorbent and elastomeric ingredients, such as carboxymethylcellulose, which remain the mainstay in managing simple wounds in 2008 (Sharman 2003). Dressing technology continued to advance based on the principles that wound products should not only provide a moist wound environment, but also have the ability to absorb excess exudate, eliminate wound dead space, provide thermal insulation and a bacterial barrier and do no harm to the wound (Seaman 2002). Hydrogels that are made up of 80-90% water, cross linked with polymer were introduced along with foam dressings that are capable of absorbing large volumes of wound fluid and alginates that are derived from brown seaweed and used to pack exuding or bleeding wounds (Sharman 2003).

CONTEMPORARY TRENDS IN WOUND MANAGEMENT

In 2008, wound dressings comprise the dressings already described, along with composite/combined dressings that can assist in a combination of processes simultaneously, such as autolysis and exudate management. Silver impregnated dressings and cadexomer iodine dressings have been developed to address the issues associated

with wound bed bacteria (Sussman 2006) and wound care research is now focused on technology such as growth factors and scar free healing (Ellis 2008). There has also been a significant improvement in the management of wound beds with the introduction of principles to manage non viable tissue (T), infection and inflammation (I), exudate or moisture imbalance (M) and wound edges (E), known as the TIME principles (Schultz 2003).

The concept of wound cleansing also advanced through the ages from the ancient use of wine and vinegar, to contemporary practice that recommends avoiding certain antiseptics in wound care and cleansing, as current research has demonstrated toxicity to cells (Gottrup & Leader 2004). Alexander Fleming suggested in 1920 that the value of the antiseptics should be weighed against their toxicity in tissues and it is therefore of concern from my observation, that antiseptics such as vinegar, first introduced by Hippocrates between 460 and 377BC (Gottrup, Leader 2004) is still being recommended in wound management in 2008. In order to optimise wound management it is not only essential to implement moist wound management principles and introduce wound management products that promote these principles, but to provide consistent wound management practice that is also based on the principles of wound healing. The principles include defining the aetiology of the wound, controlling factors that affect the healing process such as poor nutrition, medication side effects, anaemia or co-morbidities such as rheumatoid arthritis or diabetes, selecting appropriate moist wound dressings and planning for the maintenance of the healed wound (MacLellan 2000). When these issues are not addressed appropriately, wound healing is further delayed. (Carville 2005)

EPIDEMIOLOGY

Despite the advancements in wound care and practice, the management of chronic wounds remains a challenge, as a result of the duration of the wound aetiology and the issues surrounding chronicity. The healing rates of chronic wounds vary from 4 months to 4 years or more, with the longest recorded ulcer duration being over 60 years (Moffat 1995). Chronic wound aetiologies vary, with the most prevalent being lower leg ulcers of venous or arterial aetiology, diabetic foot ulcers and pressure ulcers (Harding 2002).

Incidence and Prevalence rates

According to Elliot, McKinley and Fox (2008) the international overall incidence of pressure ulcers is reported to be between 1% and 11% and from 3% to 22% in hospitalised patients. These data are reflected in Australian figures (Elliot et al 2008). Prevalence surveys conducted in Victoria between 2003 and 2006 revealed overall rates for pressure ulcers from 17.6% to 26.5% (Elliot et al 2008).

The incidence of leg ulceration is reported to be approximately 0.15 to 2% of the population world wide (Soldevilla 2006) and an Australian study conducted in Perth reported a prevalence of 0.62 per 1000 population (Baker 2005). The prevalence of leg ulceration greatly increases with client age, although a significant proportion of individuals under the age of 65 years suffer chronic leg ulceration (Soldevilla 2006). The average age of individuals with leg ulceration in Spain is 76.4 years and 72.1 years and in Ireland, with approximately 19.3% of venous ulcers affecting people under age 65 (Soldevilla 2006). In Australia, 90% of patients with leg ulcers are 60 years and older

(Baker 2005). The ratio of venous leg ulcers in males to females is approximately 1:1.6 and appears to be similar world wide (Soldevilla, 2006).

A wound prevalence survey conducted in Western Australia in 2007 quantified the prevalence of acute and chronic wounds across the state. Examining 2777 hospitalised clients 49% had one or more wounds at some point during their admission. The survey included acute and chronic wounds, with the largest category identified as acute wounds, equating to 31% followed by pressure ulcers 10.9%, skin tears 7.9%, other wounds 6.7%, leg ulcers 2.6%, burns 0.6% and malignant wounds 0.5%. This study focused on the prevalence of wounds in the hospital setting and the recommendations made as a result of the survey include increased access to wound education, clinical expertise and clinical based wound care. These recommendations can be transcribed into the wider community. It was interesting to note that a large proportion of leg ulcers (42%) were classified as being of unknown aetiology. This would suggest an opportunity of increasing the knowledge of treating health professionals in the assessment and management of these types of wounds (Wounds West survey 2007).

The cost of chronic wounds

The financial cost of treating chronic ulcers is difficult to estimate as a whole as there are no studies that look at the total cost of treating chronic wounds within both institutional and community settings. Rather estimates of treating wounds caused by a single diagnosis such as pressure or venous disease are available (Ellison 2002; Elliot et al 2008). It is also difficult to calculate the actual financial cost of treating a chronic wounds as there are so many variables involved, such as individual response to the

wound and its management, co-morbidities that may affect the healing process, such as diabetes or rheumatoid arthritis (Carville 2005), local factors that affect healing, such as pressure or friction, dressing costs, services involved in treatment and each individual's circumstances (Carville 2005).

The treatment of venous ulcers in Australia has been reported to cost between \$553 and \$654 million annually in Australia (Leach 2004). Pressure ulcer management in the United Kingdom was estimated to cost between £1.4 billion to £2.1 billion in 2000 and data from the Netherlands reveal that pressure ulcer treatment accounts for 1% of the entire health care budget (Elliot et al 2008). An estimated 95,695 pressure ulcers occur annually in Australia, requiring a median 398,432 extra bed-days, which equates to a median cost of \$285 million annually (Elliot et al 2008).

The social, psychological, emotional and physical costs associated with chronic wounds can be significant (Spilsbury 2007; Langemo 2005; Hyde 1999). In order to examine these issues more closely and identify quality research that related to living with a chronic wound, a literature search was conducted using Cinahl, Medline, PubMed, Blackwell Synergy, Science direct, Ovid technologies and Proquest databases, the key words *living*, *quality of life* and *chronic wound* were entered. Assistance was also sought from the university and health care facility librarians to identify other avenues to search for relevant literature, such as Internet searches, and internal database searches. Approximately 104,000 papers were identified that fit the keyword criteria and the search was refined using an advanced search tool, to identify relevant research papers. The advanced search refined the data available down to 1,140 which were analysed and using

my experience and theoretical sensitivity, I identified research papers that I believed to be relevant to this study.

The impact of chronic wounds on quality of life

There is a well established body of research pertaining to leg ulcers, pressure ulcers and diabetic foot ulcers. However, as Briggs and Fleming contend in their review of qualitative research, most studies looked the physical rather than the psychological aspects of living with a wound (Briggs, Fleming 2007).

Flaherty (2005), Walshe (1995), Douglas (2001), Ebbeskog (2001), Rich (2003) and Krasner (1995) identified issues associated with living with a chronic wound, such as pain, odour, exudate, infection and the appearance of the wound, with pain identified in as being the most significant experience. The physical burdens of living with a chronic wound and the impact on sleep, activities of daily living, social interaction, mobility, activity and body were described by Hareendran (2005), Flaherty (2005), Ebbeskog (2001), Douglas (2001), Husband (2001), Spilsbury (2007), Beitz (2005) and Hyde (1999). The psychological and social impact that the physical burdens have on the lives of individuals with chronic wounds, are described by Hopkins (2006), Rich (2003), Douglas (2001), Briggs and Fleming (2007) and Watson-Miller (2006). These include social isolation, disruption to normal life and daily living, reduced mobility, feelings of loneliness, helplessness and despair and a financial impact related to the cost for dressings, transport to and from appointments, medical appointments and district nursing services. These burdens appear to be compounded when individuals have the expectation that the wounds would heal quickly (Rich 2003; Watson-Miller 2006).

Walshe (1995), Douglas (2001), Husband (2001) and Hopkins (2004) identified coping strategies developed by individuals living with chronic wounds as *normalising*, *adapting* and *being positive toward healing*. (Ebbeskog (2001), Husband (2001) and Hopkins (2004) found that individuals learned to self manage and continually strive to free themselves from the physical burdens associated with a chronic wound through positivity and hope in order to cope with the experience. What was not explored in the context of any of the research reviewed for this study was the impact of negative or advice or inconsistent treatment on the ability of the individuals to develop appropriate coping strategies.

Despite the availability of evidence with regards to the experiences of individuals living with chronic wounds, research has found that health professionals are still providing inconsistent treatment and advice to individuals with chronic wounds, which may be influencing their ability to develop appropriate coping strategies (Charles 1995; Spilsbury 2007; Watson-Miller 2006; Harding 2002).

In a study by Husband (2001), the impact of patient/health professional relationship was explored using a grounded theory study that recruited 39 patients, 33 nurses and 14 general practitioners in England, looking at the experience of venous ulceration and how this translated into primary care. This study found that one of the greatest barriers to care for individuals with a chronic condition is that interventions and therapies are aimed at acute rather than chronic, , management This has a substantial impact on quality of life for the clients, as well as causing the nurses' frustration, when they were not achieving the desired outcome. In this instance, healing became the sole focus for the health professional and the client experience and knowledge were not taken

into account (Husband 2001). This study identified that health professionals did not focus on holistic care and required a greater knowledge in managing individuals with lower leg ulcers, but did not explore the issue of how individuals cope when they are receiving advice or treatment that is inappropriate, not evidence based, or inconsistent. The health professionals interviewed for Husband's study acknowledged that they had a lack of knowledge surrounding both the assessment and ongoing management of venous leg ulceration. However the issue was not further explored to determine why health professionals did not have the knowledge, despite the availability of best practice information and guidelines. Further, it did not explore the issue of how individuals with leg ulcers coped when they were receiving treatment from health professionals who admitted poor knowledge.

Douglas (2001), Hopkins (2006), Spilsbury (2007), Husband (2001), Persoon (2004), Walshe (1995), Watson-Miller (2006) and Charles (1995) identified that the provision of conflicting advice, care without continuity and inconsistencies of care could cause frustration, confusion, anger, fear and anxiety for the patient, but they did not explore the impact on the individual's ability to cope with living with a chronic wound.

In a grounded theory study undertaken by Douglas (2001), eight participants with venous leg ulcers were interviewed about their insight and experiences of living with a chronic leg ulcer. This study highlighted an apparent lack of understanding regarding leg ulcer management by the treating health professional as well as the issue of conflicting advice being offered to the patient by the treating health professional that focused around the dressing. While the study identified issues having an impact on the individual's experience and the importance of providing evidence based care, there was no

exploration as to how individuals cope with day to day living when they are receiving this conflicting, inconsistent and often inappropriate advice.

Although a number of studies have identified that it is essential to provide care based on best practice by health professionals who are knowledgeable in the field (Walshe 1995, Rich 2003 and Husband 2001), they did not explore further to determine why health professionals are not providing care based on best practice, why they are not translating evidence based research into practice. It was considered beyond this study to find out why the care is not being translated into practice and I resolved to explore further; what happens to the individuals with chronic wounds that are being caught up in this chaos?

Thus, while the studies discussed above have identified that conflicting advice and inconsistent care impact on the individuals living with chronic wounds, there is little research that explores the level of impact experienced by individuals living with a chronic wound and how they cope with day to day living when the advice and treatment they provide is conflicting, inconsistent or is not evidence based.

Much of the research reviewed for this study has been written by medical or nursing researchers who specialise, or have a significant interest in wound management and in my observation undoubtedly provide evidence based practice and have an expert knowledge in the field of wound management. However, this poses the question as to why, with the level of knowledge and expertise that exists in the area of wound management, that individuals with chronic wounds continue to experience conflicting or inconsistent treatment and advice, when there are a variety of specialist services readily

available to support contemporary practice? This is an area that I believe requires further research but is not within the scope of this study.

CONTEMPORARY WOUND CARE SERVICES

There are several world leaders in wound management, whose mission is to promote awareness of best practice, encourage research and disseminate information through the provision of education, publication of journals, Internet based information, conferences, funding and scholarships to assist in education. Societies dedicated to this mission were first seen in the UK in 1981, (*the Tissue Viability Society*) which progressed to the formation of other societies, such as the Oxford Wound Healing programme in 1982, the European Tissue Repair Society in 1988, the USA Wound healing Society in 1990, the European Wound Management association and Wound Healing research unit in 1991 at Cardiff. In 2002, the first association within wound care that is exclusive to Nurses, (*the Tissue Viability Nurses Association*), was launched in the UK. Although this list is not exhaustive, these associations are seen as leaders in the field of wound management and are easily accessed for information via the Internet.

Within Australia, a significant amount of work has been undertaken in the field of wound management. In 1990 a group of nurses who were interested in wound care joined together to organise a study day to improve the quality of wound care in Western Australia and the West Australian Wound Care Association (WAWCA) was established. Three years later at the International Wound Management Conference hosted by Australia and held in Melbourne, the Australian Wound Management Association (AWMA) was formed (Williams, Carville, & Morey 2005). The association is a

multidisciplinary, non-profit association consisting of people who are committed to developing and improving wound management for all individuals through education, research, communication and networks and acts as a parent body to the autonomous wound management associations in each state and territory of Australia. The association has worked tirelessly to develop standardised wound management guidelines and guidelines in the prediction and prevention of pressure ulcers as well as increasing the profile of the issues surrounding chronic wounds through media campaigns and national wound awareness (Australian Wound Management Association, 2002).

DEVELOPMENT OF SPECIALIST WOUND CARE SERVICES

As a result of the research and education provided by international leaders in the field of wound management, services that specialise in the assessment and management of chronic wounds have been developed across the world and wound care has traditionally been in the control of medical practitioners with regards to decision making for wound care (Dealey 2007). More recently, however, there has been a move towards specialist nurse led services that offer a multidisciplinary approach to wound care.

The development of specialist nurse led services such as leg ulcer clinics in the United Kingdom has resulted in improved quality of life as patients receive holistic specialist management (Edwards 2004) and the focus is now on prevention aimed at improving quality of life. A recent United Kingdom study investigated the cost and efficacy of leg ulcer care in these specialist clinics and showed that reduction in costs and improvements in healing rates can be sustained in specialist clinics staffed by specialist leg ulcer nurses (Ellison 2002).

Situating myself into the research domain

On a local level, specialist wound clinics/services came to the forefront in Victoria with the establishment of a federally funded, independent body, the *Wound Foundation of Australia* in Melbourne, in 1993. The wound clinic in which I work was established in 1995 as a result of the needs of our local community.

Allied health professionals treating clients in the rehabilitation setting often found that the rehabilitation process was hindered as a result of underlying pathology such as venous or arterial disease and associated tissue ulceration. The Doctor, who oversaw the services, recognised the need for a multidisciplinary service that specialised in the assessment and management of chronic wounds and oedema, including lymphoedema and to this end, our team was established.

The team originally consisted of experienced and interested health professionals from Physiotherapy, Occupational Therapy, Podiatry, Pharmacy, Dietetics, Medicine and Nursing and has developed over the years as a highly skilled, experienced and well recognised team of health professionals. The team originally provided wound and oedema management only to clients who were receiving rehabilitation, but due to the demand for service and recognition of the expertise of staff working in the clinic, the service has now developed to include two branches of the service, one offering specialist lymphoedema education and management and the other offering a nurse led assessment and management service to clients across the health care group and wider community who have chronic complex wounds.

Referrals are received across the region from nursing, allied health staff and medical specialists with the most significant number of referrals being received from General practitioners. The demand for our services has grown from 93 occasions of service in 1999/2000 to 857 in 2006/2007.

Access to specialist services

Due to the increasingly high demand for our specialist service, access has diminished as this is only specialist wound management service covering a population area of approximately 304,511 (Department of planning and community development 2006) and is staffed by one Division 1 Registered Nurse, one Doctor, two Physiotherapists, two Occupational Therapists and one Allied Health Assistant, with access to Dietetics and Podiatry as required. As this potentially acts as significant barrier for the implementation of best practice, the increasing demand for service, lack of funding and the need to expand the services to increase staffing and expertise must be addressed in order to provide both the community and health professionals with the resources to meet their needs.

Compounding the issues associated with access to specialist services, the poor adherence to implementing best practice may also be attributed to the cost of modern wound dressings, as many rural, regional and metropolitan areas cannot afford to subsidise the cost of treatments for their patients who, in my experience, are often on a limited income. In my observations, I believe that this may impact on the ability of health professionals to employ best practice, as they resort to cheaper, alternative treatments to reduce the cost to the client, such as using a dry dressing to manage an area of chronic

ulceration that is contradictory to best practice evidence (Australian Wound Management Association 2002).

NATIONAL RESPONSE

In an attempt to address the issues of access to resources, such as dressings and specialist services, the Australian Federal Government launched the Victorian Wound Management Project in March 2005, providing a commitment of \$558,000 over two years, to explore whether improved access to more clinically effective wound management products along with better assessment, management and treatment practices can enhance the quality of life for clients experiencing chronic wounds and reduce public health costs. While this project recognised the importance of providing early intervention, access to specialist services and subsidised dressing costs, phase one of this project, which was due to commence in 2005 and at the time of writing this thesis, had only just begun with the commission of a team to conduct an incidence and prevalence study across Victoria. Once this stage has been completed, it is envisaged that a pilot project will be undertaken to determine whether the access to subsidised wound management products in a community setting has the anticipated effect of increasing the clients quality of life and reducing service costs, with the primary focus being to gain evidence from a cost-benefit perspective. Stage Three of the project will potentially enable access to a regional and metropolitan pilot project that will provide holistic, subsidised wound management programs for people with chronic wounds. On completion of the three phases, recommendations will then be made to the Federal Health member with regards to the feasibility of providing funding for specialist services and access to subsidised

wound care products (Department of Human services, Victoria 2008). While this project has the potential to provide important data and access to specialist services, the implementation is dependent on the outcome of each phase and the benefits may not be seen for some time.

In May 2008, the problem of chronic wounds in the community was further recognised, when the Brumby government announced a \$5 million chronic wound care plan to provide older Australians living at home or in public sector residential care facilities with improved access to specialist wound care and services (Department of Human Services 2008). The initiative will provide \$3 million statewide, over a period of four years, to provide Clinical Nurse Consultant positions in wound management to service rural and regional Victorians as well as wound care training and support to staff working in district nursing or public health residential care sectors. While this is a significant advance in potentially improving access for clients and health professionals the outcome remains an uncertainty, as the use of inconsistent and conflicting treatment and advice remains a reality that must be addressed in order to ensure best practice in wound management is consistently implemented.

EDUCATION

With the provision of funding to improve access to specialist services and education based on best practice evidence, it raises the question of how health professionals are currently prepared in under graduate and post graduate studies with regards to assessment and management of individuals with chronic wounds. Although basic wound assessment and management is included within the context of Division 1 and 2 nursing training at both University and TAFE sectors, the translation from learning

to practice appears to me, to be confusing for nursing staff. Although I cannot comment on the appropriateness of course content, as this is not an area in which I am involved, I have both observed in clinical areas and discussed with nursing colleagues, the apparent confusion when it comes to addressing issues associated with assessing and managing chronic wounds (Campbell 1998, Sadler 2006). On delivering education sessions on basic assessment and management of chronic wounds to both division 1 graduates, post graduates, division 2 nurses and medical staff, it is clear to me, with the questions I receive, that the content of studies have either not met needs of staff when it comes to the holistic assessment and management of individuals with chronic wounds, or the teachings have not been put into practice.

While there are resources available for health professionals to access wound management education, such as seminars, conferences or workshops, this can pose a problem for regional and rural areas, as I have noted that a higher proportion of the education is only available in the metropolitan area. On discussing this with colleagues, it is apparent that the cost from both a fiscal and time perspective can be extremely restrictive, with travel times of up to 6 hours or overnight stays required. Within my region, one large conference is offered a year where specialists in the field of wound management from across the state are invited to speak, in conjunction with local specialists. This has not only been booked to capacity (150 - 200 participants) each year, but there has been a significant increase in demand for this type of education from nursing, medical and allied health professionals across the region, as evidenced by the feedback received at each conference. Several smaller seminars, education sessions and

workshops are offered on a local and regional basis by the specialist wound service in which I work, with over twenty such sessions completed so far this year.

Education for health professionals can also be supplemented through visiting specialist wound clinics not only for benchmarking purposes, but to upskill in the clinical aspects of wound assessment and management. I am aware that most specialist services, including the one in which I work, encourage other health professionals to visit their services, such as offering clinical placements for practice nurses, graduate nursing students, Division 1 and 2 nurses working in a variety of health care settings, Medical students, District Nurses, Allied Health professionals and General Practitioners.

As a result of increasing access to education and specialist services, it appears from my observation, that there is a growing number of medical, nursing and allied health services that consistently implement evidence based practice and have a high level of knowledge in the field of wound management, but there remains a proportion that do not. It is this body of health professionals that appear to have a significant impact on the ability of individuals living with a chronic wound to develop appropriate coping strategies through the provision of inconsistent or inappropriate treatment and advice (Charles 1995; Spilsbury 2007; Watson-Miller 2006; Harding 2002).

I have also observed that when a health professional with appropriate knowledge and expertise in chronic wound management, provides care to an individual with the chronic wound and that health professional has the authority, professional recognition or clinical leadership to facilitate change and co-ordinate care, the individual with the chronic wound appears more able to develop appropriate coping strategies. When care is

delivered by a variety of individuals or health professionals with no authority to facilitate care, individuals with chronic wounds appear less able to develop appropriate coping strategies. I observed that the cycle of inconsistent care is *enabled* as a result of the ability of health professionals *with* power or position but less knowledge or expertise in wound management to influence the care as a result of their power or position, where the health professionals with the knowledge and expertise in the management of chronic wounds may not have the power to facilitate care and are therefore unable to influence the care. On discussing this issue with nursing colleagues in the past, it is evident to me, that there is a level of frustration and anxiety when nursing staff are given directives from more senior staff with regards to the management of individuals with chronic wounds, that is inconsistent with best practice, but believed that they were not in a position that allowed them to influence the care or decision making process.

Despite the knowledge and education available, implementation of best practice is not always achieved (Case 2008). While there are many influences involved in transferring research into practice, such as policy, education, resources, behaviour, the relationship between the health professionals and the patient and the role of the consumer, (Clifford 2004) it is clear that these issues are affecting patient care.

A FAILURE TO UPHOLD BEST PRACTICE

Anecdotal evidence suggests that despite the availability of best evidence and the incorporation of this evidence into practice guidelines, health professionals are not adhering to the guidelines.

In my observation and discussions with colleagues and clients of the specialist wound clinic, individuals with chronic wounds are still being provided with advice and treatment that is inconsistent or being offered by health professionals who are not skilled and knowledgeable in the area of wound management. How individuals cope with this situation, its impact on their lives and its deleterious effect on wound healing has not been addressed.

To this end, my study will focus on the impact of living with a chronic wound and the ability to develop appropriate coping strategies when receiving conflicting or inappropriate advice and treatment.

CONCLUSION

This chapter has provided an introduction to the literature regarding wound management. Attention was given to the history of wounds; the epidemiology and the cost of chronic wounds that provided a background to the research problem. This was followed by a review of the literature related to the impact of living with a chronic wound, followed by an outline of the contemporary specialist services, resources and education available to health professionals. Finally the issues associated with evidenced based practice were presented. The next chapter will provide an introduction and outline of the methodology used in this study to address the research question identified.

CHAPTER 3

METHODOLOGY

INTRODUCTION

This chapter provides discussion of grounded theory methodology and the methods used to investigate the impact of living with the chronic wound. The purpose of this study was to generate a theory that is grounded in the individuals' interpretations and perceptions of their experience of living and coping with a chronic wound including the impact of having to live with a chronic wound. The emergent theory grounded in the data subsequently can be used in planning and delivering effective and satisfying patient care. Grounded theory was thought to be the most appropriate method to be, as it allows the exploration of social processes that present with human interaction and illuminates how participants make sense of their experiences and interactions. It is seen as the ideal vehicle to address the issues the impact of living with a chronic wound has on the life of an individual and the coping strategies they develop as a result, for the purpose of gaining understanding and developing an explanatory grounded theory.

The chapter will also describe recruitment of participants, sampling, data collection and constant comparative analysis methods that are consistent with the grounded theory process, study rigor, ethical considerations and the strengths and weaknesses of the study.

QUALITATIVE RESEARCH AND SYMBOLIC INTERACTIONISM

Qualitative research in the study of human life was established in the 1920s as a field of research in its own right, encompassing a variety of disciplines, fields and subjects (Denzin 1998). Qualitative researchers emphasise the socially constructed nature

of reality, the relationship between the researcher and what is being studied, and the situational constraints that shape inquiry (Denzin 1998). Qualitative research therefore is an interpretative naturalistic approach that supports the use of many perspectives and methods in investigating non quantifiable human and social reality.

Rationale for using grounded Theory

Grounded theory as an inductive naturalistic qualitative research method was chosen for this study as opposed to quantitative methodology. Grounded theory is characterised by its comparative nature and systematic but flexible manner which drives collection and analysis of data, that allows the emergence of theory grounded in the data. My aim was to develop a theory grounded in the data and give a detailed, rich description of the area under study in order to provide a deeper understanding of how individuals cope with living with a chronic wound when they are receiving conflicting or inappropriate advice or care. The use of a quantitative methodology would be inappropriate in investigating understanding and provide explanations of human experiences as they are interpreted and given meaning in a naturalistic social and human interactive world. The differences between qualitative and quantitative approaches are summarised in table 3.1.

Qualitative	Quantitative
"All research ultimately has a qualitative grounding" - Donald Campbell	"There's no such thing as qualitative data. Everything is either 1 or 0" - Fred Kerlinger
The aim is a complete, detailed description.	The aim is to classify features, count them, and construct statistical models in an attempt to explain what is observed.
Researcher may only know roughly in advance what he/she is looking for.	Researcher knows clearly in advance what he/she is looking for.
The design emerges as the study unfolds.	All aspects of the study are carefully designed before data is collected.
Researcher is the data gathering instrument.	Researcher uses tools, such as questionnaires or equipment to collect numerical data.
Data is in the form of words, pictures or objects.	Data is in the form of numbers and statistics.
Subjective - individuals' interpretation of events is important ,e.g., uses participant observation, in-depth interviews etc.	Objective – seeks precise measurement & analysis of target concepts, e.g., uses surveys, questionnaires etc.
Qualitative data is more 'rich', time consuming, and less able to be generalized.	Quantitative data is more efficient, able to test hypotheses, but may miss contextual detail.
Researcher tends to become subjectively immersed in the subject matter.	Researcher tends to remain objectively separated from the subject matter.

Table 3.1 Qualitative versus Quantitative Approaches (Neill 2007 Accessed 5.7.2008)

It is common among researchers to associate grounded theory with symbolic interactionism. The theory of symbolic interactionism conceptualises 'that humans live in a symbolic environment as well as a physical environment and that humans acquire complex sets of mental symbols' (Winchester Nadeau 2001), and the emphasis is therefore on the relationship between mental and social processes. The importance is placed not on whether something has actually occurred, but the meaning attached to those

events (Winchester Nadeau 2001). Based on the work of Chicago school pragmatist, G.H.Mead, Herbert Blumer, a student of Mead, further developed this theory of human behaviour and identified three premises on which symbolic interactionism rests (Becker 1990).

The first premise is that ‘human beings act toward the physical objects and other beings in their environment on the basis of the meanings that these things have for them’ (Blumer 1969.p2).The second premise is that these meanings arise from social interaction and communication between individuals (Denzin 1998) and thirdly, that the meanings are ‘established and modified through an interpretive process’ (Denzin 1998).

Blumer also identified six predominant images associated with symbolic interactionism, which signify the unique nature of this approach where society is seen in terms of action as opposed to social structure or culture, interaction is seen as the creator of behaviour rather than an expression, the definition of objects as physical, social or abstract, the perception of humans as actors rather than reactors, where human action is processual, formative and understood in terms of interaction and the present is integrated with the past (Lauer 1977).

Following from this theoretical perspective, Blumer classifies the methodological principles, which apply to symbolic interactionism, as being ‘applicable to every facet of scientific research from the prior theoretical orientation of the researcher to the interpretation’ (Lauer 1977). Blumer places particular emphasis on remaining in contact with the empirical world throughout research and continually reiterates the importance of interaction and social reality as a process (Lauer 1977).

A student of Herbert Blumer, Anselm Strauss further substantiated and expanded upon the theories of symbolic interactionism through the continued application of this processual concept. Lauer (1977) explains that Strauss;

has made his analysis in terms of process, the symbolic interactionist nature of the process, the perspectives of the actors involved, and the social organisational context. Since human life is a matter of symbolic interaction processes, appropriate methods of study must be found. Strauss' response was to move away from complex statistical analyses and advocate a 'grounded' approach, in which the research itself would be a process of interaction between theory and concepts on the one hand and participation, observation and interpretation on the other hand (Lauer 1977).

Essentially, the theory of symbolic interactionism has been perceived as being the foundation upon which grounded theory was established. It is to be noted however, that Glaser (2005) has refuted the necessity for the use of symbolic interactionism, or any other theoretical perspective, to guide analysis. Within Glaserian Grounded Theory method, Glaser (2005) claims theory resulting from the reality of persons behaviour and concerns should be allowed to emerge without adherence to a theoretical orientation, such as Symbolic Interactionism. Glaser (2005) argues that if symbolic interactionism institutionalises Glaserian grounded theory as its own, this reduces the power of Glaserian by ignoring its roots based in a concept –indicator model (Newman 2008).

Grounded theory was first developed by sociologists, Anselm Strauss and Barney Glaser in 1967 during an observational study of how hospital staff dealt with dying patients (Strauss 1987). There has been some controversy since the development of grounded theory and debate over the method diversified by Strauss and Corbin. In particular, Glaser argues that the addition of selective coding by Strauss and Corbin (1990) forces data into a framework rather than allowing the theory to emerge through

open and theoretical coding. The concept of grounded theory and the constant comparative method of coding is not disputed, however, for the purpose of this study, I have chosen to follow the coding paradigm developed by Straus and Corbin (1990) as I found their explanations easier to follow as a novice researcher.

CODING PARADIGM

The concept of a coding paradigm for information collection was introduced by Strauss (1987), to function as a reminder to code data for relevance and further adapted by Strauss and Corbin (1990) using headings of *causal conditions*, *phenomenon*, *context*, *intervening conditions*, *action/interaction strategies and consequences*. *Causal conditions* refer to the events or incidents that lead to the occurrence or development of a phenomenon. The coding paradigm was used in the study where identification of *conditions* was assisted by cues, such as ‘because’, ‘since’ or ‘as’ and phrases, such as ‘on account of’. The *context* represents the location of events that pertain to a phenomenon along a dimensional range and the set of conditions where the strategies are taken to respond or manage the phenomenon. *Intervening conditions* refers to the broad conditions bearing on action and interaction strategies, including time, space, culture, economic and technological state, career, history and individual biography. The action/interaction strategies refer to the response to a phenomenon under a specific set of perceived conditions and the consequences are the outcomes of those actions and interactions (Strauss & Corbin 1990).

In presenting the core categories it was essential to clearly define each of the categories within the context of the coding paradigm, to facilitate an understanding of the

intense impact that living with a chronic wound has on the individual as a holistic human being embedded in a social, cultural, experiential and interactive human world. This impact is substantiated through participants' accounts and interpretations of their experiences, gathered throughout the interview process.

Grounded theory allows for the systematic discovery of a theory from social research data (Glaser, & Strauss 1967) and the formulation of theoretical interpretations that are grounded in reality (Strauss & Corbin 1990). A grounded theory is one that is discovered, developed and verified through the collection of data and through constant comparative analysis, allowing the theory to emerge. In order to determine the relevance of a grounded theory within the field of study, the theory must meet the four central criteria of fit, understanding, generality and control as defined by Glaser and Strauss (1967), Glaser (1978) and Strauss and Corbin (1990). To meet the criteria, a regimen of systematic techniques and procedures of analysis such as theoretical sensitivity, theoretical sampling, constant comparative analysis, including theoretical coding, memoing and incorporation of a coding paradigm (Strauss 1987), is essential.

The aim of the grounded theory is to develop a theory that emerges from human experiences within a social interactive and symbolic world. 'The purpose of a grounded theory is to specify the condition that gives rise to specific sets of actions/interactions pertaining to a phenomenon and their resulting consequences' (Strauss & Corbin 1990.p 225), which in turn provide deep understanding of the phenomenon under investigation. This understanding and deep illumination of a social phenomenon leads to the development of a theory that has explanatory power.

GROUNDED THEORY METHOD

The approach used for this study incorporated the methodical use of grounded theory techniques and processes such as theoretical sensitivity, theoretical sampling, collection of data and constant comparative analysis of the data which included open, axial and selective coding. Data collection and comparative analysis was concurrently undertaken with the use of interviews and field observations (Strauss 1987). These techniques and processes will be outlined below.

THEORETICAL SAMPLING AND SENSITIVITY

In order to provide information rich cases that allowed the development of an in depth study, a purposeful sample was initially selected from individuals over the age of 18 years who were admitted to the clinical setting for the management of a chronic wound(s). Subsequently, the selection of participants was based on the emerging data and the 'concepts that have proven theoretical relevance to the evolving theory' (Strauss & Corbin 1990.p.176). This meant that constant comparative analysis and data collection was joint and ongoing. As conceptual categories with their properties and hypothesis of relations among categories emerged, further sampling was sought until saturation of categories and their properties was achieved. Diversity of emergent categories with their properties was sought in this study by recruiting individuals that varied in age, chronicity and causes of the wound, sex, the variety of services received and residential locality

In order to 'develop a theory that is grounded, conceptually dense and well integrated' (Strauss & Corbin 1990.p.42), it was essential to combine the research question of *how individuals cope with living with a chronic wound and the impact that has on their lives* with theoretical sensitivity. Theoretical sensitivity refers to 'personal

quality of the researcher and indicates an awareness of the subtleties of meaning of the data' (Strauss & Corbin 1990). Professional experience, literature and personal experience are all sources of theoretical sensitivity that allows the researcher to draw on experience, insight and past readings in order to recognise important data, to give meaning to the data and allow theories to emerge.

As I have specialised in the field of wound management for the past 12 years, I believe that my experience and expertise brings a depth of understanding that has allowed me to glean a richer and more insightful knowledge base from the data. Past experiences in both my professional and personal life have brought qualities to this study that presents another source of theoretical sensitivity. For example, my experience as a district nurse in the past has allowed me to understand the difficulties faced by regional and rural nurses when they do not have access to specialist services or are faced with time constraints that do not allow them to provide holistic care each time they visit a client.

My personal experience of injury has increased my sensitivity toward the experiences of others and the necessity to reconstruct a world that allows for the changes that result from injury or illness. This experience assisted me during the comparative analysis to see emerging category and property relationships and general hypotheses that otherwise might not have been thought of and thus explore more deeply and comprehensively (Strauss& Corbin 1990).

My familiarity and experience within the field of wound management also comes from constant review of literature pertaining to the field and this knowledge provides a further source of theoretical sensitivity for this study (Strauss & Corbin, 1990).

Techniques used to enhance theoretical sensitivity included the use of basic questioning, (using the Who? What? Where? When? How? How much? and Why?), word, phrase and sentence analysis, the use of comparison techniques such as the 'flip flop' (whereby a concept was turned upside down to imagine the opposite), systematic comparison and the technique of 'waving the red flag' to ensure that nothing was taken for granted and therefore allowed the data to open up to be fully explored (Strauss & Corbin 1990).

PARTICIPANT PROFILES

Twenty participants were recruited in this study in accordance with both the university and Health Care group ethics proposals. Participants were aged between 18 and 92 years of age and in a regional city and rural areas of Victoria, with 16 females and 4 males interviewed. Participants were recruited during their active involvement with the specialist wound clinic.

Participants interviewed for this study had chronic wounds with a variety of aetiologies including pressure ulcers, venous leg ulcers, arterial leg ulcers, mixed venous and arterial leg ulcers and pyoderma gangrenosa. The wound duration ranged between three months and up to sixty years. Eleven participants received wound care from the District Nursing Service, five attended their own care and four had their GP and/or practice nurses attending their care. All participants care was overseen by their GP until referral to the specialist wound clinic, upon which time wound care was overseen by myself, as the clinical nurse consultant. All participants were referred to the specialist wound clinic at some time during their care, with thirteen of the participants no longer receiving wound care at the time of interview, as their wounds had healed one participant

requiring surgical intervention, one diagnosed with a wound malignancy and referred to the surgical team, four still receiving ongoing management through the wound clinic and at the time of writing up the data analysis, one participant has sadly since deceased.

Participant profiles are summarised in table 3.2.

Sex	Age	Wound aetiologies	Wound duration	Primary Wound care service <i>NB: All participants received a variety of these services often simultaneously</i>			Still receiving services	Specialist wound clinic input
				District Nursing service	GP/Practice nurse	Attend own care		
Female	80	Venous leg ulcer	8 months	Yes			No	Healed within 3 months
Female	45	Pyoderma gangrenosa	2 years	Yes				Ongoing
Female	87	Venous leg ulcer	60 years			Yes	No	Healed within 6 months
Female	66	Arterial leg ulcer	5 months			Yes		Ongoing
Female	72	Mixed aetiology leg ulcer	1 year			Yes		Ongoing
Female	92	Venous leg ulcer	7 years	Yes				Healed within 2 months
Female	78	Pressure ulcer	6 months	Yes				Healed within 4 months
Female	69	Venous leg ulcer	10 years			Yes		Healed within 6 months
Female	69	Venous leg ulcer	5 years	Yes				Healed within 8 weeks
Female	71	Venous leg ulcer	3 months	Yes				Healed within 6 weeks
Female	67	Mixed aetiology leg ulcer	3 years		Yes			Healed within 10 months
Female	59	Venous leg ulcer	8 months		Yes			Healed within 3 months
Female	77	Venous leg ulcer	11 months	Yes				Healed within 4 months
Male	18	Pressure ulcer	9 months	Yes				Required surgical intervention
Male	72	Venous leg ulcer	2 years	Yes				Healed after osteomyelitis diagnosed and treated
Male	68	Mixed aetiology leg ulcer	1 year		Yes			Pt deceased
Male	62	Venous leg ulcer	3 years			Yes		Diagnosed with malignant wound on assessment
Male	79	Venous leg ulcer	18 months	Yes				Healed within 3 months
Male	77	Mixed aetiology leg ulcer	5 years		Yes			Ongoing
Male	82	Pressure ulcer	4 months	Yes				Healed within 3 months

Table 3.2: Participant profiles/Sample variability

SETTING

Interviews were conducted either in the participants' homes or the health care facility in accordance with the participants' wishes at a mutually convenient time. Eighteen of the twenty participants requested their interviews to take place at their homes and the remaining two requested interviews to take place at the health care facility. Data were collected through the audio recording of unstructured and informal interviews that lasted between 1 and 1 ½ hours.

DATA COLLECTION PROCESS

Generation of data in studies utilising grounded theory is a dynamic process, which continually changes and evolves depending on the data generated. During this study, data were collected using instructed, open ended questioning in interviews where the participant was asked how their life had been affected by having a chronic wound and what sort of coping strategies they had developed in response. This question began with the initial cause of the wound and the participant was encouraged to discuss the life challenges they encountered as a result of the wound. Data were also collected using field observation, where participants were observed during the interview, with regards to facial expression, body language and the interaction with their environment. Observations were not recorded during the interview, as I believed this would have been disruptive to the interview process, but observations were documented as soon as possible after the interview was complete

Initially data were generated through one interview, observation and analysis of that data led to further data collection. The analytical questions formed during the initial collection process guided the search for more data. The process of data collection and

analysis occurred simultaneously through this study using a constant comparative method.

DATA ANALYSIS AND THEORY DEVELOPMENT

Following each interview, data were immediately transcribed and meticulously analysed word by word, line by line, constantly compared and extensively coded according to the coding paradigm previously described (Strauss & Corbin 1990). The immediate analysis of data through a microscopic approach, rather than an overview, was essential in order to minimise the omission of key categories, and therefore lead to the development of a conceptually dense theory (Strauss 1987).

MEMOING

The process of data collection was accompanied by the frequent recording of memos which consisted of my thoughts regarding the nature of the data, codes collected and relationships they may have, or any other ideas considered relevant at the time. The recording of these memos was essential in the discovery, development and formulation of a grounded theory (Strauss 1987). The recording of memos occurred immediately following each interview, as I believed that recording of notes during the interview may have been disruptive and not allow the participant to fully express their thoughts. Memos were referenced with regards to the number of the interview, observations, and the date on which the data was collected. Further memos were recorded during comparative analysis of the transcribed data as ideas and thoughts were stimulated. Memos remained conceptual and were modified during the comparative analysis to reflect the emerging categories and codes that in the process were collapsed and abstracted according to their relationships and provided a process to identify when a code was saturated.

TRANSCRIBING

Interviews were audio taped and transcribed verbatim by the researcher. Tapes were identified by a coded number only and kept secured in a locked filing cabinet at all times when not in use. Tapes were destroyed once data were transcribed.

DATA CODING

Coding of data occurred following each interview. During the analysis, 83 codes were originally identified and are outlined in Table 3.3. The codes in the later phase of the research were related and collapsed to form conceptual categories and further data collection and comparative analysis led to their rich thickness and saturation.

Sees initial event as minor or insignificant	Minimisation by health professionals	Physical event occurs before action taken	Lack of knowledge	Increased knowledge
Increased self care	Loss of independence	Relying on others	Physical events	Inexperience
Physical appearance	Body image	Odour	Exudate/leakage	No control over body
Self concept	Loss of control	Everyone tells you what to do	Anger	Frustration
Forced to change living arrangements	Forced to accept help	Loss of power to make decisions	Loss of voice	Loss of choice
Empowerment	Social adjustment	Losing interest in others	Loss of social interaction	Loss of interest in everyday things
Financial burden	Cost of dressings	Cost of district nursing	Amount of dressings used, overuse by nurses	Accepting of cost in order to heal wounds
Conflicting advice impacting on financial burden	Resistance to treatments r/t cost	Cost of dressings plus 'normal bills'	Associated costs such as medical bills, taxis	Disruption to 'normal' life
Accepting /resigning to situation	Time disruption	Inconvenience	Search for understanding	Searching for a reason
Fear of contamination	Fear	Fear of amputation	Fear of injury/reinjury	Fear of unknown
Experiential knowledge	Knowledge not recognised	Nobody can see me	Nobody's listening	Wound dominance
Self blame	Adapting	Comparing to others	Narrowing of world	Conflict
Inconsistent advice	Anecdotal treatment	I'll do it myself	Do they know what they're doing?	Who do I listen to?
What do I believe?	When will this heal?	Information or lack of shared by health professional	Conflicting advice impacting on finances	Search for a cure
Feeling unclean	What aren't they telling me?	Recognition is empowering	Clothing	Embarrassment
Social adjustment	Altered behaviour by family and friends	Concept of burden	Information	The nurse and Dr are in charge
Inappropriate advice	Inappropriate treatment	Always careful		

Table 3:3 Codes identified during Open Coding

This initial process of comparing and contrasting codes is referred to as **open coding** or unrestricted coding of data, to produce concepts that fit the data (Strauss 1987). At this stage, interpretation was tentative and concern was not so much on the initial interview, so much as where the data would lead. Modification of concepts occurred through later analysis (Strauss 1987). Through constant comparison and analysis, the identified codes were collapsed or modified according to their relationships and interactions and the similarities and differences identified running through each code. Throughout the analysis, data was coded according to the paradigm previously described and this coding paradigm has formed the basis for the development of a framework for the core category.

In order to ensure the success of open coding, the data was constantly questioned with regard to what the data was pertinent to, which category each incidence or event related to, and what was actually happening in the data (Strauss 1987). It was essential during open coding, to remain reserved in committing to initial codes, as those which appeared significant at first, appeared irrelevant during later stages. Further interviews ensued as codes were identified and the content was guided by questions and hypothesis arising from the previous interviews.

The categories that emerged from the coding process were of two types: sociologically constructed codes and in vivo codes (Strauss 1987). Sociological constructed codes were those I formed as the researcher, based on constructions and in vivo codes were those constructed by the participants (Strauss 1987).

Once the concepts of categories began to emerge through theoretical sampling, the data was coded on a higher level, one category at a time, in terms of the emerging

patterns and relational and variation coding. This process is referred to as **axial coding** and resulted in ‘cumulative knowledge about relationships between the categories and other categories and subcategories’ (Strauss 1987). Axial coding took place during the initial stages of open coding, but became more prominent as open coding was conceptualised (Strauss 1987). Both open and axial coding occurred simultaneously as the data were constantly compared and contrasted. It was during this stage that the coding paradigm allowed the integration of categories to occur (Strauss & Corbin, 1990). A simplified example of the use of the coding paradigm can be seen in Table 3.4:

Causal condition/event	Phenomenon	Context	Intervening conditions	Action/interactional strategies	Consequence
Infected wound	Pain	The pain is intense	Action is constrained as the intense pain is occurring during the night and the person lives alone and has no access to help	The person waits until morning before calling for assistance	An increased waiting time before treatment is commenced and a prolonged pain experience and discomfort for the person.

Table 3.4: Example of Coding Paradigm use

During the coding, my thinking process was constantly moving from inductive thinking to deductive thinking, where dimensions of properties were proposed and while comparing events, attempts were being made to verify the deduction (Strauss & Corbin 1990).

As data constant comparative analysis continued, it became clearer that participants were describing living with burdens associated with having a chronic wound,

that the wound care dominated some aspects of their lives, the level of information was widely varied and this impacted on their lives, their normal life was constantly disrupted, minimisation of the wound and its care was experienced, social life was disrupted and there were issues around the care they were receiving that impacted on their lives and it was under these headings that the data was collapsed.

SELECTIVE CODING

After several months of data collection and constant comparative analysis, I was faced with the task of beginning to integrate the categories at a higher, more abstract level of analysis to form a dense theory, known as the process of selective coding (Strauss & Corbin 1990). In order to achieve the integration of data, it was necessary to identify a story line, relate the subsidiary categories around the core category using the coding paradigm, relate categories at a dimensional level, validate the relationships against the data and fill in the categories that needed further refinement or development (Strauss & Corbin 1990). In order to identify and formulate a story line that made sense of the data, the transition from describing the area under study to conceptualising the story analytically proved to be quite challenging as I attempted to ensure that the data reflected the events described and the theory was allowed to emerge. During the process of selective coding, concepts were constantly compared and analysed, relationships identified and verified which then led to the emergence of two core categories from the data, *Struggling to Endure a Wounded Body* and *The Trajectory of Care*. In order to clarify concepts and relationships, the systematic grounded theory procedures were followed, which also resulted in their verification. I constantly returned to the data to look for evidence, incidents or events that either supported or refuted the emerging concepts or

categories. Negative instances of actions and interactions were also examined in the data to reveal the conditions under which they occurred and determine whether it was failure or change in action/ interaction or variations pointing to new thoughts that needed to be followed (Strauss and Corbin 1990). Constant testing by constant comparison of hypothesis against the data allowed building of theory.

Categories were arranged and rearranged in terms of their relationships to the coding paradigm which allowed a descriptive and dense story to be told and relationships between properties and dimensions to be identified. A combination of inductive and deductive thinking was used to allow constant movement between the questions and allow the theory to emerge (Strauss & Corbin 1990). During the inductive and deductive thinking process necessary to integrate the data, several patterns began to emerge, which I did not immediately recognise and it was only on discussions with my supervisors that the patterned differences became clearer, which led to further questioning and thinking but allowed me to relate the data on conceptual and multidimensional levels.

While relating the data and constantly comparing and contrasting within the categories, a question began to emerge as to how individuals cope with chronic wounds when health professionals do not follow best practice and access to specialist services is limited? This was the basis on which the substantive theory of *Weathering the Storm*, was developed.

THEORETICAL SATURATION

The process of constant comparison of the data, coding and memo writing was continued throughout the coding process until theoretical saturation of each category occurred, which meant that there was no new information emerging relating to categories,

the category development was dense as all elements of the paradigm were accounted for and the relationships between the categories were established and validated (Strauss & Corbin 1990).

LITERATURE REVIEW

As a nurse working and studying in the field of wound management for some time, I had a background of knowledge with regards to current literature, which was essential for theoretical sensitivity and this background enabled the identification of previous research within the field of study, as well as providing theoretical and conceptual frameworks to guide the study. Although an extensive literature review was not carried out until the core category had developed, in order to avoid undue literature influence in the emergence of categories and theory, some literature was reviewed throughout the study to compare the concepts emerging in the data with those in the existing literature to validate the emerging categories, generate a more dense theory and determine the level of significance within the current body of knowledge.

RIGOUR

Glaser and Strauss (1967:7) state that

“one canon for judging the usefulness of the theory is how it was generated and we suggest that it is likely to be a better theory to the degree that it has been inductively developed from social research. We also believe that other canons for assessing a theory, such as logical consistency, clarity, parsimony, density, scope, integration, as well as fit and its ability to work, are also significantly dependent on how theory was generated. They are not, as some theorist of logic-deductive persuasion would claim, completely independent of the processes of generation”

Equally Strauss and Corbin (1990) explain that in order to evaluate the theory that has evolved from the grounded theory study, it is essential to meet the standards of research within the context of qualitative research and the complexities of social

phenomena. It is important, therefore, that scientific canons, such as significance, theory-observation compatibility, generalisability, consistency, reproducibility, precision and verification that are used to evaluate quantitative research should be modified or redefined to fit qualitative research in order to fit realities and the complexities of social phenomena (Strauss & Corbin 1990).

While the scientific research standards are used as the benchmark for judging research, these scientific standards have been challenged and redefined to suit the evaluation of qualitative research (Guba & Lincoln 1981; Sandelowski 1986). Canons, such as reproducibility, these cannot be directly related to qualitative studies as these studies can never be exactly replicated as quantitative research can. As a result of different moments in time, individual differences, situations, environment and the like, it is not possible to reproduce a qualitative study exactly. One may be able to study the same within the same context or the same concepts and achieve similar results, but never exact results.

Given the same theoretical perspective of the original researcher and following the same general rules for data gathering and analysis, plus a similar set of conditions, another investigator should be able to come up with the same theoretical explanation of a given phenomenon (Strauss & Corbin, 1990.p.251).

The criteria for judging the rigour of grounded theory is based on validity, reliability and credibility of the data, adequacy of the research process and empirical grounding of the research findings (Strauss & Corbin 1990). The adequacy of the research process can be judged using the monograph outlined by Strauss & Corbin (1990) (Table 3.5) and is useful when making judgments about the components of the research

process in this study. The operationalisation of the criteria listed below, have been illustrated throughout all chapters of this thesis.

Criterion 1	How was the original sample selected? What grounds?
Criterion 2	What major categories emerged?
Criterion 3	What were some of the events, incidents, actions and so on (as indicators) that pointed to some of these major categories
Criterion 4	On the basis of what categories did theoretical sampling proceed? That is how did theoretical formulations guide some of the data collection? After theoretical sampling was done, how representative did these categories prove to be?
Criterion 5	What are some of the hypotheses pertaining to conceptual relations (that is, among categories) and on what grounds were they formulated and tested?
Criterion 6	Were there instances when hypotheses did not hold up against what was actually seen? How were these discrepancies accounted for? How did they affect the hypotheses?
Criterion 7	How and why was the core category selected? Was this collection sudden or gradual, difficult or easy? On what grounds were the final analytical decisions made?

Table 3:5 Criterion for judging Grounded Theory (Strauss & Corbin 1990.p.253)

Guba and Lincoln (1981) discuss four factors relating to tests of rigour; truth value, applicability, consistency and neutrality (Sandelowski 1986). Guba and Lincoln (1981), (as interpreted by Sandelowski, 1986), discussed and critiqued four criterion by which research rigour is evaluated namely; Truth value or internal validity, Applicability or external validity, Consistency or reliability and Neutrality or objectivity (Sandelowski 1986). As Guba and Lincoln (1981) have suggested that in qualitative research, credibility should be the criterion against which truth value is evaluated. It is important that when descriptions and interpretations of experience are presented, that they are

immediately recognised by those who are going through the experience and others can recognise the experience when confronted by it (Sandelowski 1986).

According to Sandelowski (1986) and Guba and Lincoln (1981) while the above mentioned criterion could be adequately used to evaluate qualitative research rigour, such criteria are inappropriate to be used in their original form to evaluate quantitative research. To this end, Guba and Lincoln (1981), as discussed and supported by Sandelowski (1986) proposed that truth value, Applicability, Consistency and Neutrality be respectively substituted when evaluating qualitative research with the criterion of Credibility, Fittingness, Auditability and Confirmability. These criteria have been considered to be more appropriate and realistic in the evaluation of research that investigates human and social phenomena which cannot be controlled, entirely objectified or decontextualised.

In this study, credibility, or truth value lies in the discovery of the participants experiences as perceived and interpreted by them and as they are presented in this study. Thus the human phenomena presented in this study are participant oriented rather than the results of theory testing or a priori hypothesis and concept testing. Credibility is also enhanced by prolonged engagement with the participants. In this study, prolonged engagement was achieved through the long period which I took to complete this study, through comprehensive interviews undertaken and by careful observation made during the interviews that added insights into the process of data collection and analysis. In addition, I had prolonged cognitive and reflective engagement with the data during the constant comparative analysis that assisted me in examining, pursuing and verifying emerging concepts, subcategories and categories and avoiding biases by following the

systematic research processes of grounded theory. As the researcher, I am of the view that my creativity and theoretical sensitivity helped me to ask relevant and penetrating questions of the data, construct and follow hypotheses by interrogating the data, which led me to gain new insights and arrive at new theoretical abstractions, as well as to identify biases about the phenomena under investigation.

Credibility and fittingness was achieved through constantly checking the representativeness of the data through the constant comparative method, triangulation across data sources and data collection procedures ensuring that the descriptions contained both typical and atypical elements, deliberately trying to disprove the data and obtaining validation from the participants (Sandelowski 1986)

Credibility or truth value is enhanced when such findings are recognised by those who have or are experiencing such human phenomena. The preliminary findings of this study have been presented in a variety of forums and conferences where I have received enthusiastic and passionate feedback from people who recognise the participants' perceptions and interpretations as presented in this study, through their own practice or in some cases, experiences. Grounded theory does not require that the researcher return to the participants to verify the original transcriptions. Verification is inherent in grounded theory via the use of its systematic processes and constant comparative analysis.

Fittingness or applicability of the findings, is possible in contexts outside this study, where similar human phenomena exist. It is argued that the general can be found in the particular or the particular can reflect the general. As I have disseminated these study findings, I found that the feedback of the audience affirmed the view that the particular

human experiences presented in this study did reflect the experiences of other non participants' experiences of the phenomenon.

Auditability or consistency in this study is evident from the introduction to the conclusion. I have clearly described my 'decision trail' where other researchers can follow the events in this study and understand their logic. It is also my view that I have described and justified what I have done in the process of this study in an honest and comprehensive way. For example, I have given an explanation of how and why I became interested in investigating this human phenomenon, the aim and purpose of the study and the process of the investigation in general, such as the selection and characteristics of the participants and how data was analysed.

As presented above, I have achieved credibility, auditability and fittingness and thus have also achieved confirmability and neutrality in this study (Sandelowski 1986).

STRENGTHS AND WEAKNESSES

One of the strengths of using grounded theory for this study is that this methodology allowed me to investigate a phenomenon multidimensionally and in great depth, to find the great diversity that exists in human life and therefore illuminate the complexities of human experience and interactional relationships within a social and cultural context. The processes and techniques facilitated me to develop theory/theories that not only shared a deep understanding of the phenomena but also provided an explanation of why things happen, the way they happen and therefore different social models can be developed to resolve issues or provide relevant solutions to social problems. Grounded theory is an approach that provides the scope that enables the researcher to undertake a comprehensive investigation of the phenomena, whereas other

methodologies may be restrictive (Strauss & Corbin 1990) and not provide a knowledge that reflects a deeper understanding of the phenomena under investigation, as grounded theory allows the researcher to abstract in order to make sense from the data.

The ease of developing rapport with participants allowed them to feel comfortable in retelling their experiences as they interpreted their meaning and perceived such experience. This enabled me to gain comprehensive and rich data and this is identified as a further strength of this study. My experience and expertise in the field of wound management provided theoretical sensitivity which assisted me not only to understand the events and actions described by the participants, but enabled me to explore the data to provide a deeper and richer understanding of the area under study and is identified as a strength of this study.

One of the weaknesses of using grounded theory is that even though Strauss, Corbin (1990) and Glaser (1967) argue that this methodology is the best approach to qualitative research, it can never be exactly replicated, as it is dependent on a moment in time, as has previously discussed under the heading of rigour.

A further weakness identified in this study was that as an inexperienced researcher, there was the potential that I may not have been able to faithfully follow the processes and procedures of grounded theory and therefore may not have captured critical elements of the phenomenon to produce a dense and meaningful theory. Similarly certain elements may not have been examined deeply enough to produce a thick category and the theory may contain some biases as a result of my inexperience, as I may not have used the grounded theory techniques appropriately and exactly and took everyday knowledge for granted therefore missing critical elements (Strauss & Corbin 1990).

The potential risk identified within my ethics application, although classified as minimal, was the relationship between the participant and myself as the researcher, as I was also the participants treating nurse in the specialist wound clinic. Having an established rapport with individuals had the potential to introduce bias, as they may not have been able to express concerns freely particularly with regards to current services. Existing relationships between the participant and the researcher may potentially have influenced the ability of the participants to freely express and rather express what they felt the researcher wanted to hear. As identified in this study some participants had a perception of professional dominance and fear of retribution which has the potential to bias expression, although this did not appear to be apparent in any of the interviews conducted.

As the study was being undertaken in my area of practice, I found it difficult to distance myself from the data to allow adequate description and conceptualisation of the story during the selective coding process and to choose the core categories between the phenomena that presented. Although theoretical sensitivity is identified as strength, it can also be viewed as a weakness where my experience may have prevented me from seeing things that were obvious or routine in the data or prevented me from letting go of categories that I felt were important but not necessarily reflected in the data.

Transcribing the data from taped conversations was also noted as a potential area of concern particularly when tapes were difficult to hear as a result of the quality recording or background noise. The use of tape recordings for interviews may have potentially discouraged participants from expressing their opinions freely for the fear of

having those thoughts recorded, although this was not apparent in any of the interviews conducted.

ETHICAL CONSIDERATIONS

Ethics approval was sought and gained from both RMIT University and the health care facility (Appendix 1 and 2). The contents of ethical considerations are detailed below with regards to informed consent, privacy and confidentiality, risk, benefits and vulnerability, securing of data and dissemination of results.

INFORMED CONSENT

Consent was gained from participants to participate in this study in accordance with ethical considerations. Potential participants were identified by the researcher and the names given to the RN Division 2 attached to the health care facility, who then approached potential participants, administered the consent forms (Appendix 3) and plain language statement (Appendix 4) according to the Health Care Group Guidelines. Participants were then asked to consider participating in the study and discuss this participation with family, friends and other health professionals. If the participant agreed to participate, consent forms were signed in the presence of 2 disinterested witnesses. Under no circumstances were the participants coerced into making a decision.

Participants were informed of their rights to decline to participate in the study process at any time and assured that their required care would not be jeopardised, should the decision to withdraw be made. Participants were invited to discuss any complaints or problems encountered, with the manager of the health care facility and were supplied with written information regarding the complaints mechanisms, in accordance with the Health Care Group guidelines. All participants approached to participate in this study

agreed after consideration and consultation with families and no participant withdrew during the course of the study. No complaints were received with regards to the processes involved in recruitment for this study or the interview process that ensued.

PRIVACY AND CONFIDENTIALITY

Interviews were recorded for the purpose of obtaining accurate data. All recordings remained confidential and tapes were played by the researcher using headphones in order to prevent other persons from listening to the conversation. Tapes were identified by number only and secured in a locked filing cabinet at all times when not in use by the researcher. Tapes were destroyed once data was transcribed.

All data remained confidential and participants were not identified in any way. Data were identified by a randomly allocated number only. A record of identification numbers was kept by the researcher in a password protected computer program, with the researcher and supervisors being the only people with access to this password. The code numbers allocated to participants was not included in standard medical records. No names, addresses or other forms of identification were accessible to anyone other than the researcher. Data pertaining directly to the study were not included in the standard medical record. Participants have not been identified in the final report written up from the research.

RISKS/BENEFITS AND VULNERABILITY

Vulnerability of participants was considered in the study to be minimal risk as a result of the dependent nature of the relationship being that where the researcher was also the past or current treating nurse. As patients depend on the care provided by the nurse, the participants became vulnerable as a result and on that basis, by addressing this

dependency, we also address the issues of vulnerability. An attempt was made to reduce the vulnerability and dependency associated with this relationship via the following strategies:

- The RN Division 2 attached to the Health Care facility administered the consent forms (Appendix 3) and plain language statement (Appendix 4) according to the Health Care Group Guidelines.
- Informed consent forms were signed in the presence of 2 disinterested witnesses. Participants were actively encouraged to discuss participation in this study with family, friends and other health professionals
- Under no circumstances were the participants coerced into making a decision.
- Participants were informed of their rights to decline to participate in the study process at any time and assured that their required care would not be jeopardised, should the decision to withdraw, be made.
- Participants were invited to discuss any complaints or problems encountered, with the manager of the health care facility and were supplied with written information regarding the complaints mechanisms, in accordance with the Health Care Group guidelines.

DATA ACCESS AND SECURITY

Data pertaining to the study remained secure at all times when not in use, with the researcher and supervisors being the only people with access to this data. Data remained in the care of the researcher and was locked in a filing cabinet when not in use. The researcher alone had key access and was responsible for the security of all data. The

researcher and supervisors have access to data directly pertaining to the study. Data recorded on a computer has an access code known only to the researcher and supervisors.

DATA RETENTION

Data will be held in accordance with RMIT policy, for a period of 5 years.

DISSEMINATION OF RESULTS

Once the study is completed and passed as a Masters thesis, it is my intent to publish the results in an international wound management journal. Preliminary results have been presented at conference level and it is my intention to present the results of the study at a future national wound management conference. Any presentations or publications will be in a form such as to protect the anonymity of the participants.

CONCLUSION

This chapter has provided discussion of grounded theory methodology and the methods used to investigate the impact of living with the chronic wound in order to generate a theory that is grounded in the individuals' perceptions and interpretation of their experience of living with a chronic wound to be used in planning and delivering effective and satisfying patient care. The chapter has also described recruitment of participants, sampling, data collection and the constant comparative analysis method that are consistent with the grounded theory process, study rigor, ethical considerations and the strengths and weaknesses of the study. The experiences of individuals with chronic wounds including the impact of living with a chronic wound on each individual and the coping strategies they develop in response were examined using grounded theory and illuminated how participants made sense of their experiences and interactions and will be discussed in chapter 4, *Struggling to Endure a Wounded body*.

CHAPTER 4

STRUGGLING TO ENDURE A WOUNDED BODY

INTRODUCTION

This chapter describes the impact of living with a chronic wound within the core category of '*Struggling to Endure a Wounded Body*'. Participants' experiences are discussed within the framework of five physical burdens described by participants that consist of pain, odour, exudate, infection, and oedema. The impact that the physical burdens have on the every-day lives of individuals living with chronic wounds and the coping strategies they developed in response to these burdens will be explored.

THE STRUGGLE TO ENDURE A WOUNDED BODY

To begin the story of each individual' journey, participants were asked to recall the events which either precipitated or caused the initial wound. Each participant retold events with a clarity that indicated that this was a major event in their lives.

Initial causes of the wounds ranged from a simple trauma, such as a knock to the leg on a garden tap or an unintentional scratch, to a spontaneous eruption of the tissue with no actual event attached to it.

I just knocked it while I was out in the garden it didn't seem like much at the time. (P9P1L3)

It just appeared. I don't know how it got there (P12P8L5)

Responses to the initial injury ranged from the application of a 'band aid', leaving the skin open to the air in the traditional method of dry wound healing or the application of products such as mercurochrome, betadine or antiseptic lotions and creams or antiseptics. Throughout each interview it was noted that both the individuals and health

professionals predominantly minimised the initial injury or onset of the wound. The concept of minimisation will be discussed further in Chapter 5.

Well I didn't do much with it really just put dettol and a bandaid on it thinking that it would heal (P13PIL10)

The stories that evolve from here are uniquely individualised experiences that encompass a multiplicity of events. Although each participant's story is unique, the themes that emerged from the data formed the basis for the core categories, as each participant recounted the physical events that impacted on their lives, the resulting disruption to normality and the impact that the health information available to them had on their journey.

Although it is difficult to separate the physical from the psychosocial, emotional and cultural impact each physical event has on participants, it is essential to observe the level of each event in order to understand and fully appreciate the impact it has on an individual's life. It is also important to keep in mind that the 'normal' social, psychological, economical, cultural and environmental influences that impact on every day living, will continue to flow through each individual's life, as they did prior to the onset of the wound, as depicted in diagram 4:1. This diagram represents the trajectory of 'normal' life before the onset of the wound and while 'normal' social, psychological, economical, cultural and environmental influences continue to flow through their lives, the physical burdens and care associated with the wound bears down on 'normal' life, and is depicted later in this chapter as diagram 4:2.

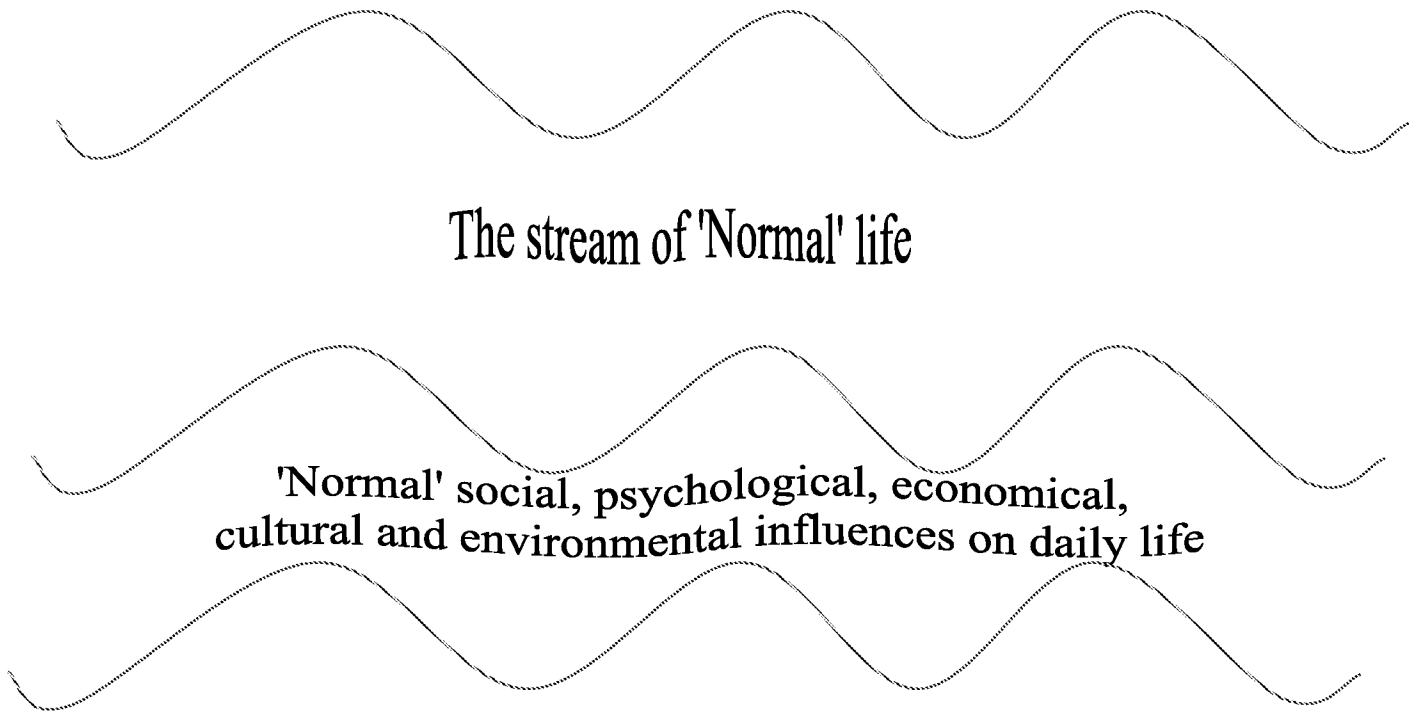


Diagram 4:1 The Stream of Normal life

PHYSICAL EVENTS

Within the context of physical events, participants described life with a chronic wound as revolving around, pain, odour, exudate, infection and oedema management. These physical events impact on activities of daily living in particular mobility, sleep, independence and function, social interaction and psychological and economical burden. Flaherty (2005), Walshe (1995), Douglas (2001), Ebbeskog (2001), Rich (2003) and Krasner (1995) have similarly identified these physical issues as being associated with living with a chronic wound and describe the impact of each burden on every day life, but do not provide a deep understanding of the impact of these issues when individuals are provided with inconsistent or conflicting treatment and advice.

In order to fully understand the concepts described by each participant, it is important to clarify the burdens associated with each physical event and the strategies and tactics developed by participant to cope with these burdens. These burdens have been identified in this study as pain, odour, exudate, infection and oedema.

Pain

The first of the physical events described by participants as having an impact on their lives, is pain. Flaherty (2005), Walshe (1995), Douglas (2001), Ebbeskog (2001), Rich (2003) and Krasner (1995) identified that pain was the most significant physical event experienced by individuals living with chronic wounds. This present study supports that pain is a significant experience; however, participants described the other physical burdens they experienced with equal importance.

In order to fully understand the impact of pain, it is important to clarify the causes of wound pain, the importance of experiential knowledge in coping with pain, the methods of pain relief employed by individuals and health professionals and the impact that pain has on the individuals' ability to function.

Aetiology of wound pain

The description of wound pain can be indicative of wound aetiology. Descriptors are often used as a diagnostic tool during wound assessment, in conjunction with clinical observation (Carville 2005). For example, if a patient with a lower leg wound describes the pain as being sharp or extremely painful and the clinical appearance of the limb is consistent with a reduction in arterial supply, such as thin, shiny, hairless skin and thickening of the toenails, the pain descriptor is a valuable indicator that the wound may

be related to a reduction in arterial supply [that being of arterial aetiology] (Moffatt 1998).

Lower leg wounds related to chronic venous insufficiency may be described as being painless or as an intermittent dull ache but can also be described as sharp, stinging, shooting or throbbing pain (Krasner 1998; Carville 2005). Such descriptors can cause confusion to the health professional if pain aetiology is being used as the determining factor in diagnosis.

Pressure ulcers may be described as burning or stinging in the initial phases of tissue destruction, or as a dull throbbing pain or absence of sensation in the latter stages of tissue destruction as a result of damage to nerve tissue (Quirino 2003). Individuals with neuropathic disease, such as that seen in Diabetes, may experience little to no wound pain, numbness, or a sensation of burning or tingling that occurs as a result of nerve damage (Krasner 1996).

Individuals presenting with chronic wounds from other aetiologies, such as vasculitis (inflammation of blood vessels often associated with rheumatoid arthritis) may describe their pain as intense and extremely painful as a result of the inflammation (Armitage 2004). Those with less common aetiologies such as pyoderma gangrenosa (idiopathic disease often associated with inflammatory bowel disease or rheumatoid arthritis) may describe pain as intense and severe (Carville 2005). Participants interviewed for this study had chronic wounds with a variety of aetiologies including pressure ulcers, venous leg ulcers, arterial leg ulcers, mixed venous and arterial leg ulcers and pyoderma gangrenosa.

Describing the Pain

The description of wound pain can also be dependent upon the condition of the wound bed (Carville 2005). For example, with an infected wound, the pain may be described as stinging, burning or excruciating. This descriptor, in conjunction with the clinical appearance of the limb, such as increased heat, redness, swelling and exudate and the clinical presentation of the client with fever and malaise, is used in the diagnosis of infection (Falanga 2006). The level of pain associated with an infected wound was clearly described by participant 4, when recollecting the experience;

It just stung and burnt. It was like someone was sticking hot needles into my leg. I found out later it was the infection and once the antibiotics kicked in it felt much better (P4P2L17-18)

Other descriptors of pain that may indicate either aetiology or the condition of the wound, is the description of a tight, pulling, drawing or irritating feeling which may be caused by a dry wound bed or the presence of necrotic tissue (Kahl 2004). This was described by one participant whose wound had been left open to the air, causing discomfort until the wound was dressed with a product that provided a moist wound healing environment;

It was just like someone was pulling out all the time it was just pulling and pulling. But once they put that ointment on, well it was like it let go or something. It looked worse because it was all gooey, but it felt much better. (P19P2L9-10)

Participants descriptions of the pain varied from ‘burning’ (P9P2L1), ‘aching’ (P5P1L17), ‘stinging’ (P10P1L14), ‘stabbing’ (P16P1L12), ‘electric shock’ (P11P2L19), ‘throbbing’ (P1P1L4) or an ‘occasional twinge’ (P19P2L17). Other participants reported very ‘little pain’ (P15P1L16) and described the pain as being ‘no worse than an aching joint’ (P4P1L19).

Participants description of the pain often caused them to reflect on moments of extreme pain and I observed that while participants were narrating their experience of pain, that they were clenching their fists, tightening their jaw, had dramatic changes in facial expression or rubbed the wound area almost in attempt to soothe the memory. The meaning attached to the memory of each episode of pain appeared to be one of unpleasantness and distress for some participants, whereas others described the pain with little observed expression or gestures.

Participants description of pain frequency and duration also varied with each individual. When describing the detail of the pain frequency and duration, participants descriptions varied from the pain occurring ‘intermittently’ (P20P2L16), ‘constantly’ (P12PIL14), ‘occasionally’ (P9PIL17), or ‘all the time’ (P14PIL12).

Participants who had arterial leg ulcers reported the pain to be worse at night in both intensity and duration as compared to the pain during the day. This has been identified as being consistent with the diagnosis of arterial insufficiency (Moffatt 1998).

You know its funny, I don’t really feel it in the day, but it sure lets me know at night. As soon as I go to bed and my legs are up for a while, it starts to hurt. I thought it was just because I had nothing else to occupy my brain, but now I know its because the blood can’t get there properly when I lay flat (P17PIL19-21)

Descriptors of pain frequency and duration from those participants who had venous leg ulcers varied from intermittent and occasional, to constant and unrelenting. Pain frequency and duration was reported by participants with venous ulcers as being worse during the day than at night and was often relieved by elevation of the limb.

It always feels better when I can put the leg up (P18P10L3)

Of those participants who had lower leg ulceration associated with mixed venous and arterial aetiology, the descriptions of pain frequency varied from constant to intermittent, depending on the position of the limb, individual activity levels, the condition of the wound, type of dressing and compression. For example one participant reported an increase in pain frequency associated with walking and another reported an increase in pain frequency when resting. Other participants reported an increase in pain level and frequency associated with particular dressings or differing levels of compression therapy, such as bandaging or compression stockings. The variation in pain descriptors and pain levels according to the variables described is consistent with the contemporary evidence (Carville 2005).

How participants described their pain varied with each individual and appeared to be based on wound aetiology and the condition of the wound bed, as well as each participant's past experience and knowledge relating to pain. In describing the experience of pain, each individual's pain experience differed and appeared to be based on their past and learned experience and knowledge (Michael-Titus 2007). For example, female participants compared their wound pain to that of childbirth, describing childbirth as 'excruciating' (P10P4L11) and in comparison leg ulcer pain was described as being 'a little sore' (P20P2L7). Conversely those who had not experienced childbirth or severe pain in their lives described the pain associated with their chronic wound as 'intense or unbearable' (P15P3L12), as this was the worst pain they had experienced in their lifetime.

It was just so painful. I can't say it was as painful as when I had my babies but it was still jolly sore (P16P2L4)

It was just the worst pain. I can't remember ever having anything like it before (P1P2L15)

Experiential knowledge can also be gained through social action and interaction and the way an individual describes pain may be influenced by this learned knowledge, where they compare and contrast their situation to that of others (Douglas 2001; Husband 2001, Hopkins 2004). For example, participants interviewed for this study stated that they often compared their pain levels and the type of pain they were experiencing with relatives, and friends, neighbours, acquaintances and health professionals. In comparing and contrasting types of pain with others, participants identified with their own pain and reported feeling comforted in their belief that there were others worse than them, or that their pain was worse than that of others.

I remember sitting with my sister and talking about different things that had caused us pain, you know like having kids or I remember when I broke my wrist. My sister had never had kids, but she said her worst pain was when she had a dry (tooth) socket. Well I've heard they are very painful and I told her that that's what my leg felt like, you know (P2P2L11-14)

STRATEGIES TO MANAGE THE PAIN

While listening to and observing participants describing their pain experience, it became clear to me that pain had a significant impact on the day to day life of the individual. In order to understand the impact of pain on day to day living, it is important to clarify the strategies and tactics used by participants to cope with the pain they were experiencing. Participants described strategies they employed to relieve pain, which impacted on normal daily life and consisted of positional changes to taking analgesic medication.

Positional changes

Participants reported relying on their experiential knowledge to relieve pain caused by leg ulcers, by experimenting with various methods of positional changes, such

as elevating the limb on a footstool for short periods of time, or elevating for longer periods by going to bed during the day, lying on the couch or elevating the limb on a chair when having meals. If these positional changes were not effective, participants reported trying other methods such as dangling the limb in a dependent position, wriggling the toes or feet and walking.

If I just dangle the leg out of the bed for a while the pain settles, but once I get it back in the bed, off it goes again (P4P8L12-13)

As well as relying on their own experiential knowledge and self experimentation, participants also reported being given a wide variety of advice with regards to positional changes by family, friends, carers, neighbors or health professionals which was often contradictory or made the participants pain worse.

Everyone kept telling me to put my leg up and rest. They didn't understand that every time I put my leg up the pain got worse. They just wouldn't listen. (P5P8L1-12)

My doctor told me to rest with a leg up as much I could. The district nurse said I should do this too. Well that was one day, the next day and other nurse told me that I should be getting up and not sitting down so much. One would tell me to get up one would tell me to sit down what was I supposed to do? When I visited the (specialist wound clinic) I got told to increase my walking and they explained why. It was really common sense so that's what I did and it helped (P14P8L12-17)

Analgesia

While some participants found that positional changes were adequate to relieve pain, others did not and used analgesia to manage their pain. The type of medication and frequency of administration varied for each participant according to each individual's needs, their experiential knowledge and the type and severity of pain. Participants reported taking analgesia either regularly, intermittently or only when the pain became too strong or unbearable.

I take the panadol with all my meals and before I go to bed. It seems to keep the pain settled. (P8P4L1-6)

I take something (analgesia) every now and again. When I think I need to I suppose. (P16P12L3-7)

I only ever take the panadol when the pain is too bad I don't like taking tablets so I wait until it gets really, really bad and when I need it I take it. (P10P7L2-3)

Participants reported taking a variety of medication such as Panamax, Ibuprofen, Digesic, Tramadol and Morphine. Some participants reported initiating their analgesia regime, whereas others reported commencing analgesia on the recommendations of family, friends or health professionals such as pharmacists, nurses or doctors.

I just took whatever I had in the cupboard. I tried panadol because that's what I had. That didn't do much so I went to the supermarket and got some other tablets. They were ok for a while. (P6P5L21-23)

I've tried a few things but when I was talking to my neighbour she said Panamax helped her so I thought I would try this too. I don't think it helped that much. (P1P6L17-18)

Of those participants who self initiated analgesia, the regime consisted of 'taking a couple of panadol' (P2P7L4) when 'the pain got too bad' (P6P2L11), to taking regular panadol, or Ibuprofen during the day and occasionally at night. Participants reported that they felt confident to take analgesia without seeking medical advice as 'this is what they had always done' (P13P2L9) and 'it had always worked before' (P4P7L2), therefore there was no reason to think that these past treatments would not be effective in managing wound pain.

Of those participants who managed their pain with intermittent 'simple analgesia' such as Panadol or Ibuprofen, some reported that this was completely effective all of the

time whereas others felt that it was not. Those who felt that this regime was not effective, stated that they believed that the simple analgesic medication ‘should have been strong enough’ (P8P6L14) to manage their pain and that the increase in pain was brought on by activity or ‘being on their feet for too long’ (P11P6L20) and that a positional change or rest was all that they needed, rather than seeking stronger analgesia.

I really didn’t think I needed anything stronger than panadol, as this has always worked for me, but not this time. I thought it should have been enough to get rid of the pain. I don’t want stronger things in case I get addicted. I thin it was more painful because I was doing a bit much so I figured a bit of a rest should do the trick (P6P8L19-11)

Many participants reported being afraid of taking too much medication due to side effects such as ‘dependency’ (P3P5L6) or ‘constipation’ (P20P10L2); some would wait until the pain was unbearable before they took any medication. For some participants concerns regarding side effects such as dependency, sedative effect or nausea were allayed through discussion with their doctor and they therefore took their medication according to the doctor’s advice, whereas others made the decision to take the medication only ‘when I really needed it’ (P4P10L7) for fear of becoming dependent based on what they were told by family, friends or health professionals, the context in which they were told and their interpretation of that information.

My doctor explained to me that I wouldn’t get addicted if I took the tablets the way he told me to. Well I did that and I didn’t get addicted. (P12P15L4)

I’ll only take it when I really needed it you know. (Daughter) told me that it is addictive and when I asked the nurse, she said well yes it is, so I try not to take too much. (P4P10L7-8)

When this participant was asked if the nurse had explained how to take the medication safely, she replied that she did not really remember, but she may have done so.

Codeine based analgesia, such as Panadeine was avoided by some participants as a result of the side effect of constipation, as they had previously experienced this side effect and had made their decision to ‘put up with the pain’ (P9P3L21) rather than go through uncomfortable and often painful episodes of constipation.

I don’t like to take anything with codeine in it because it mucks my bowels up. I have a friend who started off on prescription painkillers and ended up addicted I don’t want to be like her. (P12P7L19-20)

I would really just rather put up with it rather than being on strong pain killers that I can’t get off. (P8P12L1)

Some participants had made the decision not to use medication that had constipation as a side effect as it was ‘too much mucking around’ (P16P10L3) to change their diet or ‘take another pill to combat the effects of another’ (P14P9L12). Of those participants who took panadeine, some supplemented their diet with increased fibre or fluids or took medication such as laxettes, Senokot or Metamucil *in* order to relieve side effects, whereas others did not experience the side effects and therefore made no changes.

I just take some Senokot and eat a bit more fruit then I don’t have to worry about the bowel” (P5P4L17)

But I can’t eat much: it’s a much more mucking around to cook extra vegetables. I’d take a laxette if I need to. (P20P9L21)

Participants reported that they made the decision to seek medical advice when simple analgesia such as Panadol was not effective in relieving their pain and the pain was beginning to impact on activities of daily living, such as housework, sleeping and social activities. Participants then made the decision to see their Doctor for advice regarding stronger analgesia.

I just couldn't take it anymore and I wasn't able to go out and do my shopping play bowls or see the grandchildren because it just hurt too much. I figured taking something stronger would let me get on with my life. (P3P12L18)

For some participants the advice consisted of being provided with a prescription for analgesia such as Digesic or Tramadol, with the advice to take as necessary, where others were advised to take analgesia regularly throughout the day. Participants reported being given advice with regards to pain relief from their treating health professionals that included use of positional changes and analgesia, but did not include use of alternative therapies such as hot packs, TENS machines or exercise, all of which are reported to be effective in assisting in managing pain associated with wounds (Sussman 2006).

EFFECT OF WOUND PAIN ON DAY TO DAY LIVING

As a result of wound pain, participants described varying degrees of impact on their normal activities, such as the use of analgesia and issues such as constipation, with the most significant being on mobility and sleep. Of the twenty participants interviewed, 16 reported pain as having an impact on their mobility with four of the 16 reporting having to initiate the use of a walking aid, which included the use of crutches or walking frame, in order to reduce weight bearing on the limb and in turn reduce pain levels.

I just can't get used to using a stick. I feel so I old but I just can't walk properly with the pain I get. The jolly thing gets in the way sometimes and I'd tend to leave it behind because I'm still not used to it. (P10P11L17-19)

Changing space

One participant recalled having to change her personal environment, as she could no longer walk to her bedroom as a result of the wound pain. With the help of family, she had a bed moved into her lounge area, so she could lie down and rest during the day and sleep at night.

I was so sick of trying to get to the bedroom to go to bed, because it just stirred everything up at night, that I had the bed moved. It may not look wonderful, but at least I am getting some sleep now. There was a couple of steps to get to my bedroom and I just couldn't make it any more. Once the leg is better, I will move back but for now this will do. The leg is much better so I am sure it won't be long (P5P13L2-7)

Sleep deprivation

Further compounding the issues associated with wound pain, was the impact the pain had on the individual's ability to sleep. The cause of sleep deprivation was reported by all participants to be as a direct result of the pain, although the actual cause of the nocturnal pain varied. Those participants with a reduced arterial supply to the lower legs consistently reported an increase in pain levels as soon as they went to bed. Lying in a recumbent position reduces the blood flow and as a result, the tissue is starved of oxygen and the body responds with a pain signal (Moffatt 1998). In response to this type of pain, one participant reported that she now slept in a chair to allow her a comfortable nights sleep

So what I do now, I get ready for bed and I go in and watch the telly and I put me foot up. I'll go off to sleep and I'll stay there. I'll leave the telly on, the heaters on and I'm warm. I go into a sound sleep and I stay there now until I wake up and then when I wake up I might go to bed or I might not. (P16P10L2-7)

Another participant reported sleeping in a chair in order to combat the nocturnal pain he was experiencing, only to be told by a treating health professional that this was not appropriate and that he should sleep in the bed.

Well I tried that love and I got no sleep at all. I laid there in agony. I thought then, who does she think she is telling me what I'm doing is wrong? She's not the one laying there in pain. So I sleep in my chair and I don't care what they say (P15P5L12)

Other participants reported sleep deprivation to be associated with a lack of distractional stimulus at night and nothing else to think about but the pain.

Sometimes it worries me to think that you know bad circulation and that I'll end up like (partner who has had a limb amputation) That's what worries me. Mmmm. No-ones ever said that it's going to happen, but it's always in the back of your mind because it hurts. You think about it at night when you can't sleep and I think it hurts more then. (P2P13L18-21)

While a minority of participants reported little or no impact to their sleeping pattern, others had to make more substantial changes during the day in an attempt to alleviate or relieve the pain or compensate for a poor nights sleep. Strategies varied from going to bed for the afternoon or laying on the couch to rest, rather than normal activities such as housework, gardening or shopping.

I have always been one to be fairly active and now I find I have to go back to bed in the afternoon just to rest the leg. I've cut down the amount of social things that I do, like meeting friends for coffee especially if I know it will be in a crowded cafe and someone might knock my leg, but sometimes I'm just too tired to go if I've had a bad night. (P18P11L4-6)

Night time is hard because I don't sleep well so I am still tired in the day. I usually go back to bed nanna nap in the afternoon. (P16P9L2-3)

As a direct result of sleep deprivation and constant tiredness, several participants reported a reduced ability to attend to daily chores. This included preparing their meals and changing their normal meal menu to include simple meals, such as sandwiches rather than cooked meals. This may, have an impact on wound healing; given that nutrition has a substantial impact on the way our bodies heal (Woodward 2008).

I just can't be bothered cooking meals anymore. To stand up for a long time hurts. It's just easier to make a sandwich or have a cup of soup. (P7P4L17-18)

My friends say I should eat better and they sometimes bring meals around but sometimes I really just don't feel like eating. (P18P8L5-6)

Participants also reported a reduction in their ability to participate in normal social activity as they were 'just too tired' (P12P16L7), which will be discussed further under the heading of 'disengagement' (Page 117). Participants reported that the tiredness they felt made them irritated and they found that the interaction with their family and friends was difficult as a result.

I am so tired and cranky I just don't want to talk to anyone. When I have visitors I really just don't want to talk to them. I used to love having friends visit but now I dread it because I'm so tired. I'm sure they understand but they don't seem to drop around as much anymore and that makes me a little sad (P8PP10L12-16)

While the issues associated with pain identified by participants in this study have also been identified in other studies that investigated the experiences of living with a chronic wound (Flaherty 2005, Walshe 1995, Douglas 2001, Ebbeskog 2001, Rich 2003, Krasner 1995), it appears the level of impact varies according to the information and evidence available. This raises the question that if individuals with chronic wounds are provided with consistent advice that is based on the best available evidence with regards

to pain relief, would the impact on their day to day lives be lessened? This question is also explored within the burdens of odour, exudate, infection and oedema.

WOUND ODOUR

Wound odour was identified by participants as having a substantial impact on aspects of their daily life. While Douglas (2001), Husband (2001), Spilsbury (2007), Beitz (2005) and Hyde (1999) identified that wound odour had a significant impact on the social and psychological aspects of the lives of individuals living with chronic wounds, what they did not identify or discuss, was the level of impact experienced by individuals when wound odour was not appropriately managed, or management advice was either not offered, or was inappropriate.

Cause of wound odour

Wound odour is predominantly caused by anaerobic bacteria with or without a wound infection (Falanga 2006) and can be managed using products such as topical antimicrobials or wound dressings containing silver or charcoal (Carville 2005). Dressings that occlude the wound can also contribute to wound odour, as wound exudate accumulates under the dressing and once the dressing is removed, there is often an odour present (Carville 2005). This odour disappears once the dressing has been discarded and the wound cleaned (Carville 2005).

Consequence of wound odour

Wound odour was described by participants as ‘embarrassing’ or ‘disgusting’ and although the wound odour is discussed here under the heading of physical events, the psychosocial impact cannot be underestimated (Douglas 2001; Husband 2001; Spilsbury 2007; Beitz 2005; Hyde 1999).

Nineteen of the 20 participants interviewed for this study, cited varying degrees of emotional response in relation to wound odour, from slight embarrassment when the nurse removed the dressing to disgust, feelings of revulsion and distress.

The smell just makes you feel disgusting. It is like rotting meat and that makes me feel absolutely dreadful. (P13P11L19-20)

How can you go anywhere or be with anyone when that smell is coming from you? People look at you, people think you're dirty and I just won't go anywhere while it smells (P19P12L5-6)

The remaining participant stated that he was not bothered by the smell:

it's only there when the dressing comes off and my sense of smell isn't that good anyway (P15P4L17)

One participant recalled an incident where she was sitting in a medical surgery waiting room to see her GP about her wound. The receptionist entered the waiting room with a can of air freshener, sprayed the area, with particular reference to the vicinity this participant was sitting. This participant reported feeling;

utterly devastated. I couldn't even tell the Doctor when I went in I was that embarrassed. I certainly couldn't say anything to the reception girl. I just felt sick. (P18P10L19-20)

Upon reciting this incident to the interviewer and as noted in field notes, it was clear that this incident still affected the participant, as I observed tears welling in her eyes while she retold her story. The participant had returned to the surgery since and states that she had always felt uncomfortable, but was never able to submit a formal complaint and she did not wish for advocacy on her behalf. . Based on this participant' recollection, it is evident that the impact the behaviour of others has on each individual is both instant and lasting.

Unfortunately this is not an isolated incidence, as five of the other participants recalled such events.

I remember when my friends visited and they kept moving away from me and looking around the house. They didn't say anything but I knew it was because of the smell. One of them got up and opened a window and I felt dreadful, so ashamed. (P7P14L3-5)

My sisters wouldn't even sit near me when they came to visit. I knew it was because of the smell. (P12P6L17)

My grandchildren won't even come near me. I see them screwing their noses up because of the smell. It makes me feel terrible. I do love them so much and I just want to cuddle them. But not if I make them feel bad because of the smell. (P13P13L7-9)

Eliminating the odour

As all participants interviewed had experienced wound odour to some degree, it was with some concern that I listened to the variety of coping mechanisms they had put into place. However, although creative in some aspects, there was an impact on their psychological well being that could have been avoided with the appropriate management and advice. One participant was being treated in the community by a team of health professionals managing her leg ulcer. She had not attended any social engagement for approximately 18 months as a result of constant wound odour. Given the appropriate advice and treatment regime by a specialist wound clinic, the wound odour had disappeared within seven days and this participant returned to social activity. While this is an extreme example it clearly demonstrates not only the impact of wound odour but the effect of appropriate management.

Another participant explained that her coping mechanism for a malodorous wound was to make sure there was always something nice cooking in the house that

would cover the smell up. Upon stating this, her daughter, who was present at the interview, stated that there was a time where no-one liked to come to visit her Mother, as;

the smell in the house was so bad, it made people feel sick. Even the grandchildren wouldn't visit (P3P11L2)

Other strategies and tactics employed by participants in order to alleviate the embarrassment associated with the wound odour included the use of talcum powders, deodorants or perfumes sprayed directly onto the dressing that would mask the odour for a short period of time, but do little more.

I put talcum powder all over my bandages every morning. It covers the smell a little bit so I can go out sometimes. (P20P13L6)

I just spray perfume over the leg. I keep a little spray can in my bag for when I go out too! (P9P7L16-19)

Given that wound odour can be managed using topical antimicrobials, appropriate dressings and frequent dressing changes, the provision of appropriate treatment and advice that is based on best available evidence is essential.

WOUND EXUDATE

The third physical event which provokes substantial emotional and psychosocial responses is that of wound exudate (*discharge from a wound*). Of the 20 participants interviewed, all had experienced episodes with excess exudate, with the degree of impact varying from minor to significant, when the exudate level reached a point where it was visibly dripping from the wound. Douglas (2001), Husband (2001), Spilsbury (2007), Beitz (2005) and Hyde (1999) have also identified wound exudate as having a significant impact on social and psychological well being; however few recognised the effect of poor exudate management.

Definition

Wound exudate is an essential aspect of wound healing, as it contains the cells necessary to promote wound healing and destroy dead or decaying tissue. However, when the wound exudate is more than a 'sheen' over the wound bed, its presence can inhibit wound healing (Carville 2005). Recent research has shown that wound exudate in excess can be detrimental to the healing process by blocking cellular proliferation necessary for healing; inhibiting growth factors essential for wound closure and contains some proteins that break down the extra cellular matrix vital for cell movement and re-epithelisation (Falanga 2006). Increased exudate levels can result from high levels of oedema in the tissues, high levels of bacteria in the wound or the presence of a clinical infection (Falanga 2006).

Several participants retold experiences of increased exudate levels that were consistent with high levels of bacteria or issues related to oedema level, yet participants reported that they were not aware of what had caused the increase in exudate level.

The discharge just got worse and worse, but the Doctor couldn't really tell me why. I did ask him, but all he said was we just have to keep trying different antibiotics. I don't think they made that much difference really. The legs still leaked. (P4P8L12-14)

It is unclear as to whether the participant's health professionals had actually explained the aetiology of increased wound exudate clearly to participants at the time of onset, the participant could not remember the explanation or that the explanation did not occur.

I wasn't sure what was happening and I don't remember that they told me what was going on to start with, but I think they said I had a bug in my leg and put on some special powder the discharge went right down and I didn't have to worry so much any more (P4P8L19-21)

The impact of exudate

The impact of wound exudate was retold by one participant recalling the times when her lower legs swelled to a point where not only did she have ulceration of the tissue, but had oedema to a level where it was leaking through the skin. The exudate was visibly running down her legs and despite dressings and padding around the legs to contain the exudate, it dripped into her shoes and onto the floor. Not wanting to leave wet spots on the flooring and carpet, this participant resorted to;

using my brains, to make a pair of 'boots' from plastic containers (P14P10L7).

In essence, she walked around her home every day with her feet in plastic buckets to protect her carpet. Although initially embarrassed at the thought, she stated that she had to adapt to this situation, as she could not afford to replace her carpet. When asked what she felt others thought of this, she replied that she;

Really didn't care and if they didn't like it they didn't have to come and see me (P14P10L16)

Social activity and interaction were affected as a result of excess wound exudate when there was a fear of attending a social event or engaging in normal social activities, such as grocery shopping or visiting friends and finding that the exudate had leaked through the dressings. Participants indicated that other people would think they were 'dirty' or 'unclean' when the exudate could be seen through a bandage or dressing and it was equated to incontinence by several participants.

I just couldn't go anywhere; it leaked so much it looked like I had wet myself. (P20P12L17)

I had some friends come around and they didn't say anything, but I could see them looking at the wet dressings and I remember feeling really embarrassed. (P14P11L18-19)

Sopping up

Several participants cited implementing a variety of strategies to manage the exudate levels, such as the use of nappies, pads or bulky dressings to absorb the excess fluid, but often this was inadequate in that the dressing would leak well before it was due to be changed.

I had to resort to wearing baby nappies on my legs. Nothing else would soak up the mess. Never thought I would have to wear nappies again, let alone on my legs! But it was a case of make do with what you can. The nappies worked and it stopped the mess from leaking out everywhere. (P5P11L3-5)

Given appropriate management strategies and evidence based advice and treatment, management of exudate need not be the burden reported by participants.

My legs were dripping everywhere and I couldn't see that anything would work and I thought I would be wearing nappies for ever. Then they (specialist wound clinic) put these bandages on. I really wasn't sure that it would work you know, but I had confidence in what they said because it made sense to me, so I thought I would give it a go. The first few days were amazing. The discharge leaked for about 24 hours and then almost nothing. Even after a week I could see the difference. The legs had gone right down and there was absolutely nothing coming out. It was a miracle I reckon! (P6P11L2-6)

The impact of advice

On discussing the concerns with participants, it was clear that the advice given by some treating health professionals with regards to exudate management was based on the best available evidence, whereas other advice was not. One such example of a strategy implemented that was not based on the best available evidence was a participant who was having excess exudate managed by her Doctor, with the use of nappies from toes to below knees on her lower leg. Whilst this was absorbing the exudate, it was not addressing the underlying issue of the cause of the excess oedema and a high wound bed

bacterial load. When a compression regime was implemented by the District Nursing Service and the wound bed bacterial load had reduced with the use of antimicrobial dressings, the excess exudate was no longer an issue. Given the impact of excess exudate on the day to day life of individuals living with a chronic wound, it is clear to me that appropriate treatment and advice that is based on the best available evidence is essential not only to provide holistic care but to improve the quality of life for these individuals.

INFECTION

The fourth physical event which has a major impact on the lives of individuals living with chronic wounds is infection, or the presence high levels of bacteria in the wound [wound bed bacterial burden]. Within the current literature there is a paucity of information relating to the impact of such infection. While the significance of an infection is well documented with regards to the care of individuals with clinical infections, the issues associated with quality of life and infection are not as well documented. Certainly there is little research that identifies the impact on individuals with chronic wounds when an infection or critically colonised (*described below*) wound is not managed appropriately.

Definition

In order to understand the impact these events have on each individual, it is necessary to clarify the degrees of wound bed bacterial burden. After any surgical or traumatic wounding of the skin, skin flora migrates across the anatomical landscape of the skin therefore contaminating the wound with micro-organisms (Carville 2005). Research by Schultz, Sibbald and Falanga (2003) has identified varying degrees of wound bacterial burden which have been classified as contamination, colonisation,

critical colonisation and infection. **Contaminated** wounds are defined as having non-replicating organisms present that do not inhibit wound healing (Carville 2005). However, wounds can also be **colonised**, by replicating organisms, such as *Staphylococcus epidermidis* which have been shown to have a positive influence on wound healing (Carville 2005). Occasionally the wound becomes, '**critically colonised**'. This is defined as an increase in the bacterial burden of the wound whereby healing is impaired (Falanga 2006). Symptoms of critical colonisation include increased wound pain, increased exudate levels, increased wound odour or a change in wound bed appearance in isolation or in combination (Falanga 2006). The need for systemic antibiotics can be reduced if the wound is treated prudently with topical antimicrobials at this stage (Carville 2005). **Infected** wounds are diagnosed through clinical observation and include increased heat, warmth, redness, oedema and pain, often accompanied by fever or malaise and require treatment with systemic antibiotics and daily dressings (Carville 2005).

Fear of contamination and infection

Participants reported varying concerns regarding a fear of contaminating the wound and causing an infection. Several participants reported changing behaviour in order to reduce the probability of contamination such as not sweeping the floor for fear of dust and bacteria or avoiding walking in the garden or gardening for fear of bacteria from the soil.

I think the infection came from the soil so I don't go outside without the leg being covered and I don't dig out in the garden anymore (P7P5L16-17)

Other participants related their infection to individual behaviour and stating feeling perplexed and guilty as they could not make sense of how the infection occurred.

I can't help thinking what I have done wrong. Was it that I didn't clean it properly? Did I touch the dressing and get a bug from my hand into it? I just don't know (P19P11L7-8)

If any changes occurred in the wound, particularly in the pain levels, their immediate thought was 'oh I hope it's not an infection again' (P13P12L4). This heightened awareness was reported by some participants as being the catalyst for visiting their doctor more frequently.

I seem to see the Doctor a bit more now just to get him to check it. It makes me feel better when I have someone checking and then that way if I get an infection, he will get onto it quickly and it won't be so bad as last time. (P9P16L4-6)

Getting in early

On listening to the participants recollections of episodes of infection and going over my field notes after each interview, it was clear to me that each participant experienced the issues of bacterial burden when they recalled a series of events that led to an infection. It appears that when the bacterial burden was addressed at an *early stage*, the impact of infection may have been reduced. All 20 participants described experiencing the symptoms of critical colonisation on at least one occasion, with only 10 participants reporting that their treating health professional initiated topical antimicrobial therapy (three by the District Nursing Service and seven by the specialist wound clinic). Of those 10 participants, one developed an infection that required antibiotic therapy.

Of the remaining 10 participants who experienced the symptoms of critical colonisation, four sought medical advice or advice from their district nurse. One was initiated on systemic antibiotics. The other three had no changes made in the management regime and each of these developed an infection requiring systemic antibiotics. These

three participants were told by their treating health professional that because the only one of the concurrently ‘classical clinical signs of infection’, such as increased warmth, redness, oedema, exudate and odour (Falanga 2006) was evident, they would not require any treatment.

The remaining six participants, who were attending their own wound management without district nursing or specialist wound clinic involvement and attended their doctor infrequently, did not recognise the symptoms of critical colonisation. Three of these participants reported that their wounds were not improving and changed their regimes to commence topical application of differing antiseptic lotions, such as dettol and savlon, both of which are contraindicated in the management of chronic wounds as a result of the toxicity to cells within the wound bed (Carville 2005). Another participant left the wound open to the air, which is also contraindicated in the management of chronic wounds, as the wounds require a moist warm environment in order to heal (Carville 2005). The remaining two participants did not change their regime. All six of these participants eventually developed an infection that required systemic antibiotics, with two requiring a hospital admission for intravenous therapy.

The impact of infection

During the period of infection participants described varying degree of impact from minor inconvenience as a result of taking antibiotics, to a major impact involving an increased dependence on others as a result of the intense pain, feelings of malaise and/or hospital admission.

Oh I hate taking antibiotics. They make me feel nauseated and I don't feel like eating. I know I need to take them, but oh. (P13P10L19-20)

I couldn't do anything. I had to have someone do everything for me. The infection just made me so sick. (P4P4L16)

The pain was just incredible. I couldn't stand it. I couldn't do anything to make it feel the slightest bit better. I ended up getting the ambulance and spent over a week in hospital. (P10P5L1-3)

One participant recollected experiencing an inability to perform even simple tasks such as getting a drink or preparing a meal. This reduced capacity to function in turn led to an increased dependence on others for assistance in attending tasks normally performed independently, such as showering and toileting. The psychological effect of this increased dependence was reported as one of the most difficult aspects of having a wound, when this participant articulated that one of her worst fears was to become dependent on those she loved.

I just couldn't do anything. Couldn't even get up to get a drink and I felt so awful. The pain was excruciating and I just felt dreadful. The leg was leaking and my sister had to change the sheets every morning for me. It was horrible because I like to do for myself not have to rely on everyone else. I don't ever want to be a burden on anyone. You might as well shoot me. I just don't want other people to have to look after me. (P2P12L16-20)

Following an infection, one participant reported being told by her nurse to avoid 'pottering in the garden' as the soil contained bacteria which may have caused her recent infection. This participant reported that she no longer went into the garden, a much loved past time, as a result of what this nurse had said to her.

I used to love me gardening, but I don't do it now because I am scared that I will pick up another infection and I don't want to go through that again. The nurse told me that if I kept pottering with my plants, I would get another one (infection) and I just can't risk that. I do miss it though. I look at it from the window now (P17P10L6-9)

This psychological turmoil participants were describing was evident in their body language and facial expressions. While the psychological impact described in this study is reflected in the research reviewed ((Douglas 2001; Husband 2001; Spilsbury 2007; Beitz 2005; Hyde 1999), the impact of the constant questioning of their situation, particularly when individuals are inappropriately managed or offered conflicting advice however, is not well documented.

OEDEMA

The fifth physical event described by participants as having an impact on their lives was oedema (swelling) of the lower limbs. While oedema did not affect every participant interviewed, the discussions from participants who had oedema provoked quite intense responses and could not be overlooked. Although the impact on life style has been well identified (Krasner 1998, Edwards 2003, Persoon 2004, Flaherty 2005 and Hareendran 2005, and) there appears to be little evidence that provides a deep understanding of the impact of oedema on the lives of individuals when the oedema management is inappropriate.

Causes of lower limb oedema

Lower limb oedema can be caused by a variety of conditions including, chronic venous insufficiency, lymphoedema, acute swelling related to infection, trauma or underlying blood clots, or cellulitis (Moffat 2007). Oedema can involve the entire limb or localised to the tissue surrounding the wound (Moffat 2007). The degree of oedema experienced by participants interviewed for this study varied from mild oedema, where the wound edge was oedematous and minimal oedema noted in the limb to gross oedema, involving substantial swelling of the lower leg(s).

I didn't really have much swelling. It (lower leg) was a little bit puffy by the end of the day but that was about it. (P10P14L6-7)

Both the legs were swollen so big I couldn't fit any shoes on and could hardly bend the ankle or walk. (P20P10L18)

According to the best available evidence (Moffat 2007) it is vital to diagnose the aetiology of lower limb oedema in order to provide the most effective and appropriate management as misdiagnosis can lead to tissue trauma (Moffat 2007). For example, if an individual with a lower limb ulcer is treated with high level compression, as seen in the treatment for venous leg ulceration and that individual has an ulcer of arterial aetiology, the risk of causing further ulceration and contributing to the level of ischaemia is great (Moffat 2007) This assessment, therefore, must be holistic in nature, that is assessment of the whole person not just the presenting wound. This includes assessment of vascular supply to the limbs to establish whether the arterial flow is adequate, before applying any form of compression (Carville 2005). The assessment of the vascular status can be performed by a Registered Nurse who has been trained in the process and technique of using a hand held Doppler, interpreting Doppler sounds, performing a resting ankle brachial index (RABI) and using this information in conjunction with the holistic assessment of each client (Moffat 2007). Implementation of compression in the form of bandages or compression garments has been identified as 'best practice' in the management of lower limb oedema caused by lymphoedema or chronic venous insufficiency (Moffat 2007), but can only be initiated once the client has been appropriately assessed and the vascular supply is adequate for safe application (Moffat 2007). Compression works by increasing the blood velocity in the deep veins, reducing oedema and therefore the pressure differential between capillaries and tissues, reducing

the distension of superficial veins, restoring valve function in some veins by reducing vein diameter and improving the healing rate of wounds (Moffat 1998).

Participants interviewed for this study reported that generally they did not understand the mechanisms behind compression and how it worked to reduce oedema and exudate levels as well as promote wound healing. A small number of participants reported that some of their nurses had explained this to them and all participants reported that this was explained to them on assessment at a specialist wound clinic.

Wearing compression

Participants who reported issues associated with oedema wore either compression bandages or compression garments in the form of below knee stockings. Participants reported feeling some embarrassment at having to wear compression stockings, as cited by one participant when recalled sitting in a full waiting room at the local general practice. The participant was wearing custom made compression garments and overheard someone whisper to her partner that the garments the participant was wearing were the same type someone had suggested to her that she may need. As the conversation was quite loud, the participant overheard and became embarrassed that they were discussing her, but tried to ignore their conversation. Unfortunately the couple continued to discuss how the garments looked stating quite clearly that they were 'not the most attractive things in the world'. (P5P2L18) The participant initially reacted with embarrassment, which she then said quickly turned to anger. The participant stated that she became quite cross regarding this overheard conversation and although she 'felt like saying something' to the couple, she did not. At that stage the participant stated that her embarrassment outweighed her anger and she did not feel comfortable to approach this couple and let

them 'know how she felt'. The participant was then called from the waiting room for her appointment and felt that the 'glare she gave' the couple when leaving the room appeased her anger.

Participants who wore compression garments to manage oedema reported various levels of impact on their daily live from minor inconvenience to major changes. One participant stated that wearing compression garments did not have 'much of an impact' (P1P12L6) although it 'did take a bit longer to get dressed for the day' (P1P12L7) as the 'stockings were tight and a bit hard to get on'. (P1P12L9) Other participants reported varying degrees of impact from spending 'almost an hour extra to get ready for the day' (P14P15L7) to having to 'wait for someone to come and help me get the stockings on before I can start my day' (P19P6L20).

The degree of impact was compounded when participants had co-morbidities, such as arthritis, which made it difficult to get compression garments on or off, or suffered from other medical conditions such as congestive cardiac failure, which made it difficult to bend to get compression garments on or off without becoming breathless.

I just can't get the stockings on the arthritis is too bad so I have to get my husband to help me. (P16P10L19)

For other participants, the impact was lessened when they had someone at home, such as a spouse or other family member, to help them get the compression garments on or off, but for those with less support, the impact was greater.

I don't have anyone to help me get the stockings on and off. If I get into trouble I need to call the nurses. (P5P14L17)

The impact of inexperience

The use of compression bandages rather than compression garments/stockings compounded the issues associated with wearing compression, when inexperienced or untrained staff applied the garments. One participant recalled having compression bandages applied by her nurse only to have bandages fall off after 30 minutes. Another recalled having compression bandages applied so tightly, that her pain levels ‘almost doubled’ and when the bandages came off ‘there was skin off everywhere, with blisters and sores that I didn’t have before the bandages went on’. (P12P16L19) Although this will be discussed in greater detail within chapter five, it is evident to me, both in my practice and when listening to participants recalling their experiences of wearing compression bandages, that it is vital for treating health professionals not only to be aware of the importance of compression, but to be adequately trained and proficient in its use.

As a result of the physical events described, individuals experienced varying degrees of impact on their ‘normal life’, which revolved around the care of the wound and the dressings and/or bandages they were required to wear. The impact on normal life consisted of changing routines, changing the way individuals dressed, disengagement and avoidance behaviour, which will now be discussed under the heading of the impact of physical events on normal life.

THE IMPACT OF PHYSICAL EVENTS ON NORMAL LIFE

Changing Routines

The disruption to normal life experienced by individuals living with chronic wounds varied depending on their wound management regime and the services that were in place to assist with the wound management. For those participants who had ‘simple’

wound management regimes, the impact on day to day living was less than those who had more complex regimes. Simple dressing regimes may have consisted of a weekly dressing regime that comprised removing a waterproof dressing before showering, washing the limb under the shower and reapplying a new dressing after the shower, or a daily dressing where the wound can be washed under the shower each day before applying a new dressing. For those participants, the impact on day to day life was reported as being quite insignificant.

It really isn't a drama, I take the dressing off, the leg gets wet, I dry around it and wack another dressing on when I am dry and dressed. Takes two minutes tops
(P6P13L6)

For those participants who were not able to use waterproof dressings relating to allergies, fragile skin, large areas of tissue loss that could not be covered with a waterproof dressing, or more complex dressing regimes were required, the inconvenience with showering was more significant. More complex dressing regimes may have included second daily dressings, using a topical application of a powder, then the application of a secondary dressing to cover the powder, followed by a length of cotton tubing to hold the dressing in place and a compression garment over the top of the cotton liner. Dressing the wound every second day meant that the limb would have to be 'waterproofed' in some way for the shower, which can be managed using specially designed limb protectors, that can cost up to \$70, or by applying 'glad wrap' and a large 'garbage bin liner' to the limb [up to the thigh] before the shower, securing with tape. This type of regime was common among participants interviewed for this study and as a result participants reported having to allow extra time during the day to attend to activities of daily living such as shower or dressing.

I have to cover the leg with glad wrap, put a garbage bag on my leg, put glad wrap around the top and then seal it all with tape. This takes about half an hour before my shower because of the arthritis and after all of this fussing, these it's still leaks. It does make it extra hard on a really cold day! (P11P13L7-10)

The impact on day to day living was further compounded when participants received services to assist them with wound care. Several participants managed their wounds without assistance, whereas others relied on the District Nursing Service, Practice Nurses or family and friends to assist them. For some, the impact was not reported as significant. However, others reported a significant impact and this appeared to be associated with the simplicity of the wound management regime, the skill and experience of the treating health professional or carer, or issues associated with the wound such as pain, level of exudate or the use of compression or where the dressings were being done.

Of the 20 participants interviewed, all had received input at some stage from their local district nursing service or practice nurse, with four of the participants still receiving services at the time of the interview. Several participants received the services of district nursing out of necessity, as they were unable to attend their wound dressings for a variety of reasons, such as medical, cognitive or functional issues, or felt that they did not have the knowledge or the skill to identify problems associated with the wound.

Of course, well as you know full well I can't at times do the dressings myself and you know and I have to have help to do that. (P2P10L4-5)

Waiting for care

Participants who received the district service described the inconvenience associated with waiting, as this impacted on their day to day living routines.

You just don't know when they are going to come. I can't start anything because I need the leg dressed, so I just have to sit here and wait. Sometimes they don't come until after lunch and that's my whole morning gone. A couple of times they had forgotten about me and I've had to ring to find out where they were. I lost the whole day those times. (P17P11L1-7)

Two participants reported that they were happy to accept this, as they enjoyed the district nursing visits and felt more confident and secure knowing that they had a nurse looking at the wound regularly. They also described the importance of having someone to contact if they became worried about the wound or something had gone wrong with the wound.

I am up at 7 and I usually read the paper and have breaky and I have a shower about 8.30 and sometimes I have to sit here and wait for the nurse sometimes until 10.30, sometimes 11.00. I just go out and make a coffee and come back. I've got used to it. One thing it teaches you is patience. You've got no choice. It's no use thinking oh you know I want to do this, or should be doing that. You've just got to settle down and wait. (P4P10L8-12)

Coping with strangers

Those participants interviewed who were receiving the services of district nursing also described the disruption to their day to day living that was caused by having other people in their homes. While some participants described this as being a minor inconvenience, relating to having a 'stranger' coming into their home once a week, other described this appear to have major impact as they described a 'constant barrage of people coming in and out'. (P1P13L7)

I remember counting 20 different people coming into my house over just one week. They (nurses) sometimes wouldn't even knock, just walk in and give me a fright. Sometimes I'd hear a faint noise – I'm a little bit on the hard of hearing side! And then someone would just be there. I hardly saw the same face twice. Sometimes they'd have students with them, sometimes they'd come on their own. With the woman coming in to help me clean and the nurses coming in and out, sometimes I felt like I wasn't in my home anymore – it had been taken over!

(P12P16L1-6)

When asked how this made her feel, the participant replied that this frustrated her to have people;

thinking that they could just come and go as they pleased and taking over my house. I thought it was rude and they should at least knock and let me answer the door instead of just walking in. They could have been anyone for all I know.

(P12P16L9-11)

Managing my time

The disruption to daily routine was reported as being less significant for participants who attended their local medical practice for regular dressings with the nursing staff, as they knew what time they would receive care and how long the care would take and could therefore arrange their day around this.

It's actually better than having to wait around for someone. I try to make my appointments early and that way I can have my shower, go to the nurse to get my leg dressed and looked at by the doctor if it needs to be, then get on with my day. I'm usually in and out pretty quick and it beat waiting all morning wondering what time the (district) nurses would come (P2P10L19-22)

Other participants reported an increased inconvenience as a result of attending a clinic for regular dressings, as the entire day had to revolve around the wound care, with many regular activities having to be rescheduled to fit in with caring for the wound.

Having to schedule my day around everything I have to do with the leg – I have to get up a bit earlier because the shower takes me such a long time. By the time I put the glad wrap on my leg, the garbage bag and tape it up, there's twenty

minutes gone. Then there's the fuss of showering without getting things wet. Even with the bag on sometimes it leaks. Once I've had the shower, it takes me more time to get the bag off and it's cold and wet! By the time I get dressed, 'cause I'm a bit slow anyway, it's past my breakfast time! If I've got an early appointment, sometimes I need to get up before the sun, just so I am organised to go. I see the Doctor twice a week, 'cause the nurse there dresses it and on those days, I don't really get a chance to do anything else. The riggamoroll of showering dressings, waiting for the taxi, getting in to the doctors, waiting to be seen, then getting home takes nearly all day, especially if it's a late morning appointment. I get home for a late lunch and that's me done for the day. I can't do my shopping or clean up like I would normally do. If I need the dressing done on a bowls day then that's out too (P19P14L6-17)

For those participants who no longer received district nursing or the regular attention of their practice nurse, the question was asked as to why the service no longer attended. Participants indicated a variety of reasons, including the feeling of being able to manage without the assistance and not needing a nurse to come any more, as well as the frustrations they had with regards to waiting for care and the impact this had on day to day living.

I can do the dressing just as well as the Nurse can. She comes in after I've had my shower sticks a new dressing on and she's gone. I could do that, so I talked to her to see if she thought I could manage and she said as long as I got the doctor to look at it if it wasn't getting better, that she thought I could do it too. (P19P7L19-21)

I just couldn't stand waiting around all the time. I couldn't go out and get my milk and bread until they came and sometimes they wouldn't come until lunch time. I'd have to sit and wait all that time. I know they have other people to see but if they could be there at the same time roughly everyday it would have made my life a lot easier. Sometimes I had to ring the office up to see where they were if they hadn't got there by the afternoon and sometimes they had forgotten me or put me onto the afternoon list without telling me. I got fed up and just told them I could do the leg myself. (P17P11L7-12)

Other participants who no longer had the district nursing service had discontinued the service as they had family, carers or friends to attend the dressings and described this as being much more convenient.

I don't have to wait around anymore and can just get on with things. I have my shower and (family) does my leg and I can get on with it (P9P4L17-18)

For those participants with co-morbidities that required regular medical input, or those who were caring for significant others, the impact on day to day living was reported as being significant.

Well it's difficult to keep up with appointments; you know back and forth, it's an inconvenience and that you know that's a little bit of a worry. By the time I see the Doctor for my heart, get all my tablets from the chemist, have my blood tests done and get my leg dressed, I haven't even got time to do the shopping! (P14P12L1-4)

CHANGING BEHAVIOUR

Changing the way I dress

Further compounding the inconvenience associated with care of the wound, were the issues associated with clothing and difficulties fitting footwear. This matter was reported by 18 of the 20 participants as having a significant impact on day to day life. For some participants the issue of clothing stemmed from embarrassment caused by the look of the dressings or bandages, whereas others had issue with getting clothing to fit over their dressings or bandages.

I just can't find trousers with legs wide enough to put my legs in. With all the bandages, everything is too tight, so I have to wear stretchy ones and I don't really like them. (P10P10L16-17)

The existence of a wound and necessity to wear dressings, bandages or compression garments again had varying levels of impact on the lives of the participants, with particular regards to a disruption to their normal daily life from a minor inconvenience to a significant impact.

I hate wearing these things (compression garments). They are so ugly and I'm sure people look at me because of them. (P17P12L9-10)

It's all part of the process. If I want to get the leg better, I need to wear them, so I can't see what the problem is. (P6P14L3-4)

The females interviewed, who wore dressings, bandages or compression garments on their legs reported that they had adapted by changing the way they dressed to hide any evidence of a wound. Female participants, who reported that they would normally never wear trousers, particularly in social situations, had resorted to wearing long pants instead of their chosen skirts or dresses. In three instances this was the first time in participants' lives that they had worn long pants, as they told of coming from an era where it was 'frowned upon' when ladies wore trousers. This was a difficult concept for one participant particularly;

I have never worn trousers in my life. Ladies just didn't. I don't feel right, but it's better than people looking at dirty bandages and ugly stockings (P7P14L11-12)

Another female participant who had always worn trousers had instead chosen to wear long skirts or dresses as an alternative to wearing trousers.

I have always liked to wear trousers because I think they look smart and I have never been comfortable in skirts. I've had to wear long skirts now because my trousers won't go over the bandages and at least the skirts cover them. (P16P13L5-7)

All participants reported difficulties with their attire, whether this was difficulty in finding skirts long enough or trousers with wide enough legs to accommodate the bulky dressings and bandages. Things appeared to be more difficult for the females

interviewed, given current trends in fashion, which tend to dictate how wide the legs of pants and trousers are.

If I could find trousers to fit, I would wear them, but all the trousers in the shops now have skinny legs on them. You can't seem to find the wider leg ones. Maybe the fashion will change soon and wide leg pants will come back in. I hope so!
(P5P10L2-4)

One of the male participants interviewed also reported difficulties in finding trousers that were wide enough to accommodate dressings and bandages, although he did not see this as holding great importance;

It doesn't really bother me. Who looks at me anyway? (P18P13L6)

One of the other main issues reported by participants, with regards to attire, was the lack of appropriate footwear available, particularly when they were required to wear compression bandages as a part of their management regime and found that their 'normal' footwear no longer fitted their foot. Female participants frequently cited that they resorted to wearing their husbands' slippers, or purchasing 'ugly shoes with Velcro straps' (P8P2L19) to accommodate bandaged feet.

I have a wardrobe full of new shoes and I can't wear any of them! I had to go to a wedding not long ago and got all dressed up, but I looked terrible around the feet. I had to wear those disgusting old slippers (P18P14L11-13)

Male participants reported that this was the main issue with regards to changing attire, as 'men don't wear slippers when they go out!' (P15P12L6)

I was brought up in the old school. You don't wear slippers when you go out. You wear clean and polished shoes. (P15P12L9-10)

As the result of having to change normal fashions, many of the participants both male and female reduced their social interaction, as some reported that they felt uncomfortable going into social situations when they had either inappropriate footwear or nothing that covered their bandages properly.

I don't really like going out if the dressings are showing because I think people would look at the dressings. Then comes the questions about oh what have you done and then when you tell people you've had the thing for a year, they start to tell you what to do, or someone they knew that fixed theirs with some concoction and well it's just easier not to go out. (P3P13L16-19)

I can't wear decent shoes, so I feel uncomfortable going out. I think I look silly going to the shops in my slippers! (P14P11L2-3)

Others reported that their social interaction had not changed as a result of wearing dressings or bandages, as they felt they had adapted enough to either cope with people looking, or they had changed their attire to disguise the wound and dressings.

Oh I don't care about what people say. If they don't like my shoes, they can buy me some new ones. I'm too old to worry about what other people think! (P16P12L17-18)

I still go out, because the trousers cover the dressings, so unless I pull up my trouser leg, no-one would know. And I'm not going to do that in public am I? (P9P15L3-4)

In contrast to covering the dressings up, one participant described that when she was wearing the dressing and bandages, people tended to be more careful of her and paid her more attention. While sitting in the waiting room at the doctors for example, conversations were often struck as a result of someone asking her what she had done. Her family paid her more attention and helped her out more than they ever had and she admitted that in some respects, it was OK to have the wound and dressings visible!

It's really not so bad now that it doesn't hurt so much. People help me out more because they can see I've got a sore leg. My grandchildren are more careful around me, because they can see I've got a bandage on so they are careful.

(P20P14L3-5)

Disengagement

It appears that the reduction in social engagement and interaction that participants have described in response to physical burdens of pain, oedema, exudate, odour, infection and as a result of the way they now had to dress, developed at varying levels, in order to cope with the burdens of living with a chronic wound. The impact for participants varied from minor to significant and appeared to be dependent on their level of activity and involvement in social activity prior to the onset of the wound.

Participants reported reducing social activities such as shopping or outings and for those participants who played a sport, such as lawn bowls, the reduced mobility related to pain levels directly impacted on their ability to participate in their sporting activities.

I have always played bowls and I hate that I can't join in this season – the leg is just too sore and it hurts to stand for long periods of time. I've got a stick I can use and a special thing to pick my bowls up, but it's still too hard. I try to go and watch the team as much as I can, but it makes me feel sad that I'm not in there with them. I still get to stop for a beer afterwards sometimes but I feel a bit left out when they're talking about different shots when I haven't been playing

(P11P11L16-20)

On discussing this further with this participant, it was evident that there was significant meaning attached to this participation with the bowling club and the impact on daily life was quite substantial as a result of not being able to participate.

For some participants a conscious decision was made to reduce social activities or *disengage* to an extent, as they 'knew that it would just make it hurt more' (P13P8L17) and it 'was easier if I just didn't go shopping because they (family) would only have to bring

me back early or I would be miserable’ (P10P13L4-6) This process of disengagement has also been identified (Ebbeskog (2001), Hopkins (2006) Douglas (2001)) as a coping mechanism developed in response to living with a chronic wound. It appears however, that this process of disengagement is influenced by the level of care and understanding individuals living with chronic wounds receive by treating health professionals and will be discussed further in chapter 5.

Avoidance

The avoidance of social activity was reported by several participants as resulting from a fear of reinjuring the already injured area and the potential to cause a new area of ulceration which further added to their burden. Several participants stated that they ‘lived in constant fear’ (P18P12L19), that they would ‘knock it and it will take even longer to heal’ (P9P15L17)

The degree of fear varied with each participant from simple act of ‘worry’ and that they may knock their leg when doing chores such as vacuuming, to a point where one participant no longer went to busy shopping centers during the school holidays for fear that one of the increased crowd of young children running around the shopping center, may accidentally knocked her or bump into her. The fear was that this would result in a new injury or injure the already affected area. This compounding fear and had an enormous impact on this particular participants social life, where she would not go out during any of the school holiday breaks, which equates to up to 10 weeks in the year.

I just don’t go out during the school holidays anymore, the crowds are so big and there’s little kids running around everywhere. I can see one crashing into me and hurting the leg again so I just don’t go. (P12P15L12-14)

Several of the participants reported a fear of potential to injure or reinjure when working in the garden and therefore avoided this activity. This fear was substantiated by participants who had their initial injury caused by knocking a garden tap or a scratch with a stick and by those who had indeed reinjured an existing wound or caused a new one, through an accidental knock.

I've knocked my leg and they broke out and then I got more careful about them I suppose (P3P6L2)

And I don't like shifting things a lot because you sometimes, if you're pulling anything you could pull it onto yourself. Or chairs I'm very careful shifting chairs because these are heavy ones (indicating kitchen chairs) and I avoid my gardening. (P3P7L16-18)

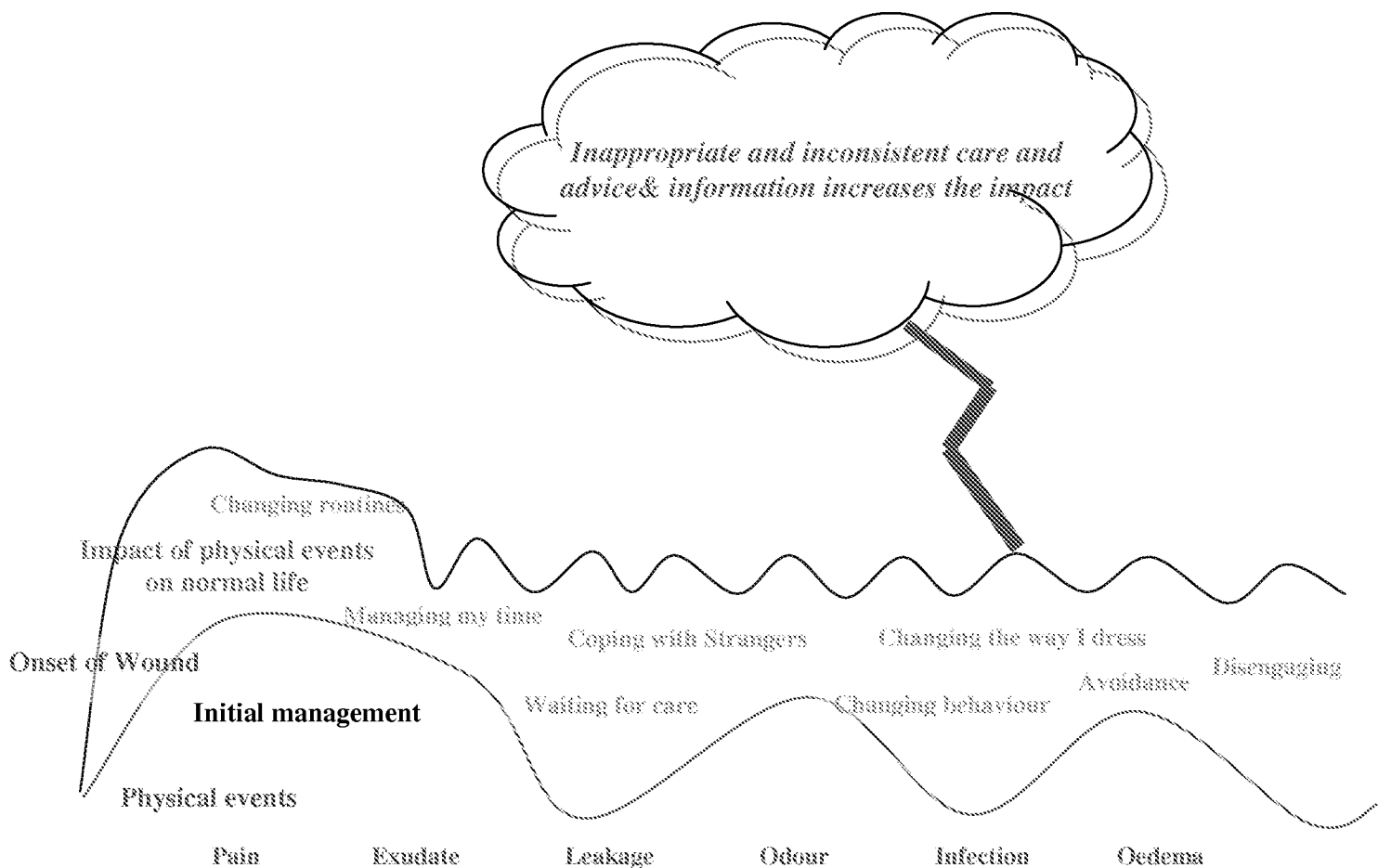
Strategies implemented in order to overcome or deal with this fear, included applying extra padding over the dressing, using a thicker dressing than would normally be warranted, wearing long trousers to protect the leg, or avoiding situations that may cause injury.

I can't vacuum clean; you see I rubbed it once with a hose of the vacuum cleaner. That didn't do any good. I stepped back on it. You can change the way you do things because you might injure it. I avoid the vacuum cleaning (P3P6L4-6)

DISCUSSION

It appears from these descriptions that individuals living with chronic wounds not only struggle with the physical burdens of pain, odour, exudate, infection and oedema, but as a result of the chronicity associated with the wound, day to day living becomes a struggle. As a result of the physical events associated with a chronic wound, participants described varying levels of impact on day to day living. For some the impact was minor, but for others it was significant and appeared to be dependent on their ability to develop

appropriate coping strategies. It appears that the burdens were compounded when individuals were provided with treatment or advice that was inconsistent, or was not based on the best available evidence and poses the question of how individuals cope with day to day living when provided with inconsistent or inappropriate care and advice and would more consistent and appropriate approach influence the way individuals cope and reduce the burden they experience? It appears that as individuals learn to live with a chronic wound; 'normal' day to day life alters as a result of the associated physical burdens. While 'normal' social, psychological, economical, cultural and environmental influences continue to flow through their lives, the physical burdens and care associated with the wound bears down on 'normal' life, as depicted in diagram 4:2.



Trajectory of life with a chronic wound

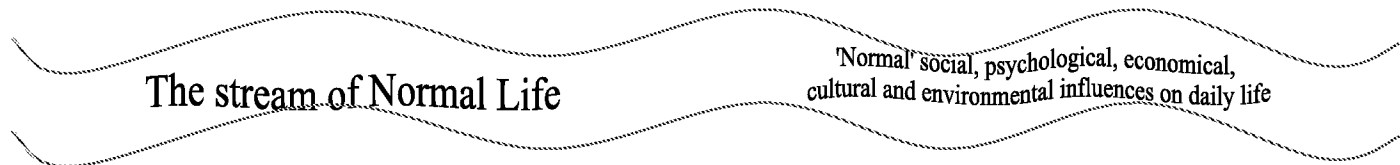


Diagram 4:2 Physical burdens associated with a chronic wound bearing down on normal life

As these burdens bear down on normal day to day life, the individual begins to struggle to develop appropriate coping strategies, which appears to be influenced by the amount and level of information and care they receive from treating health professionals. When the care they receive is inconsistent, not based on best available evidence, or is provided by health professionals who do not have up to date knowledge in wound care practices, individuals appear to be left to their own devices to cope. This raises the question as to

what impact inconsistent care and advice has on the ability of individuals to cope with living with a chronic wound and that they were provided with consistent practice that was based on the best available evidence, would their struggle to endure the physical burdens associated with living with a chronic wound, be lessened? This will be discussed in chapter 5; *Negotiating care*.

CONCLUSION

This chapter has described the impact of living with a chronic wound within the core category of '*The struggle to endure a wounded body*'. Participants experiences were discussed within the framework of the five physical burdens described by participants, including pain, odour, exudate, infection, and oedema. The discussion explored the impact that the physical burdens had on the every-day lives of individuals living with chronic wounds and the coping strategies they developed in response to these burdens. It also presented a brief insight into the struggles of enduring a wounded body when the treatment and advice they received was inconsistent, inappropriate or not based on the best available evidence. The insight into this struggle is further explored in the next chapter where the impact of inconsistent treatment or advice is described by participants in the context of their daily lives and ability to develop coping strategies.

CHAPTER 5

THE TRAJECTORY OF CARE

INTRODUCTION

This chapter will discuss the impact of living with a chronic wound within the second core category of *The Trajectory of Care*. This category explores the experience of individuals living with chronic wounds with regards to their care and is discussed in the context of the *initial care* and *layers of professional care* received. The discussion also explores the impact that conflicting, inappropriate and inconsistent care and advice has for each individual.

THE TRAJECTORY OF CARE

While comparing and contrasting the experiences described by participants with regards to their physical burdens, it became clear to me that living with a chronic wound was not only a struggle as a result of physical burden, but the journey through the wound *care* also had a significant impact on ‘normal’ life. Participants described a *Trajectory of Care* from the onset of the wound and through their descriptions I identified several ‘key’ areas, that not only appeared to impact on the individuals day to day life, but on their ability to develop appropriate coping strategies. These areas were; conflicting and inappropriate advice and treatment, continuity of care and inconsistency of care and advice. In order to provide an understanding of the impact that care has on each individual living with a chronic wound, it is essential to follow the care from the initial onset of the wound. From there, the trajectory of care progresses from initial minimisation of the wound, to a period where the wound is not healing as expected and

the individual seeks advice to manage their wound. Once the individual starts to seek advice, the trajectory of care becomes layered as a result of differing care and advice, the variety of services involved in the care and the level of informational and expertise provided by health professionals. The trajectory of care will be discussed within the context of *initial care* and *layers of professional care*.

INITIAL CARE

At the onset of the wound, participants described minimising the actual event that caused their wound, based on the appearance of the wound and past experiences. They often delayed seeking professional health care. Often they commenced their wound care based on their own experiences and sometimes on the advice of family and friends. Participants were asked to recall the initial incident or onset of the wound and of the 20 participants interviewed; 18 reported the initial injury or wound onset as being “minor” or “trivial” according to its appearance.

It was just a scratch (P17PIL10)

It was only tiny (P3PIL16)

Comparing and contrasting

In order to gauge the severity of the situation, participants reported comparing and contrasting their situation with that of others. This strategy was used from the onset of their wound and continued throughout the wound journey. As a result of comparing and contrasting, all participants reported delaying seeking professional advice.

She said she had a much worse leg than yours – yours is nothing! (P15P2L8)

I have seen other people with the ulcers and mine wasn't nearly that bad so I really didn't worry too much about it. I didn't go to see the Doctor because it didn't look as bad as I've seen before (P9P2L16-19).

The concept of comparison is a strategy employed by individuals living with chronic wounds to 'normalise' their situation (Douglas (2001), Husband (2001) and Hopkins (2004).

Minimisation

In attempting to normalise their initial situation, participants reported minimising both the initial event that caused the wound and the appearance of the wound. Participants described wound care as initially focusing around the type of dressing or topical treatment used to promote wound healing. All participants interviewed had used 'dry wound healing' as an initial treatment, such as the application of a bandaid, gauze dressing, or the topical application of betadine or an antiseptic lotion such as 'dettol' and left the wound open to the air. No participants used moist wound healing products at this stage. When asked if they were aware of moist wound healing, participants' level of knowledge varied from no knowledge to a basic knowledge of moist wound healing.

I always thought that you had to open things up to the air; you know dry the sore up and get a scab. I tried to do that with this (wound), but it only made it worse. That's when the nurses started putting those other dressings on – you know to keep it (the wound) moist. It was much better after that. (P11P6L8-11)

Expectation to heal

Participants were asked what they expected to happen once they had dressed the wound and all 20 replied that they expected their wounds to heal, with minimal intervention. The expectation that the tissue would heal appeared to result as much from personal past experience, as it did from the experience and knowledge participants gathered throughout life, where they had observed or interacted with others who had experienced similar things.

Things have always healed in the past, why would this time be any different?
(P14P1L6)

After a period of between one to two weeks following the wound onset, participants reported that they became more aware that the wound was not healing the way they had expected it to. In order to heal the wounds, they began to seek alternatives to their management.

I tried a few different things to start with, because they had always worked before. You know, I put a bit of dettol on when it first happened and covered it with a bandaid, but then when I took the bandaid off I tore a bit more of the skin, so that that was no good. I went to the chemist then and got some savlon ointment and put that on but it was a bit weepy, so I covered it with a bit of gauze, you know. Well that was no good either, so I had some sort of disinfectant cream in the bathroom, but that really stung. I had a look at the supermarket, but they only had bandaids and things and I didn't want to tear more skin, so I went to the chemist and bought a dressing from there. I can't remember what it was but the chemist said it would be OK. (P6P5L12-20)

When participants reached the stage where they realised that their wound was taking longer to heal than expected, they reported trying a variety of topical treatments including honey, vegemite, crushed aspirin, bleach, vinegar, dettol, betadine and animal products. When asked why participants chose particular treatments, it appeared that they had relied on their past experience to heal the wound with the products that were available within their level of knowledge, or on the recommendations of family, friends, carers, neighbours or health professionals.

She (friend) told me that her neighbour had a bad leg years ago and swore by Rawleighs ointment, so I had some in the cupboard and I tried it. It wouldn't really go onto the sore – it kept slipping off, so I put it on a gauze and tried that for a while. I thought it looked better but it didn't heal. I tried a lot of other things after that, some things people told me about that worked for them, like vegemite! Can you imagine? I put vegemite on it. I felt a little bit silly, but my friend said it worked for someone she knew, so I thought, well it can't do any harm. It really stung, so I only used it the once. (P19P6L6-12)

I can't believe what I have tried on this – I don't know who told me to crush as aspirin and put it on like a paste, but I did – boy did it sting! I still tried for a while with it though, but surprise surprise it didn't do much! (P7P3L9-11)

The Doctor said just to put some betadine on and leave it (P12P8L5)

One participant recalled the influence her family had on her choice of wound dressings after her son had read a newspaper article about a particular wound product and purchased the product for her to use.

My son read about this honey being used on ulcers and went out and bought me some. I was really positive about using it because it's a natural thing and I thought it must be good. It didn't really do much though. It was worth a try though (P5P8L2-4)

Participants began to describe a series of events that led them to seeking professional assistance for wound care. This tended to happen when they had become aware that the wound was not healing as they would normally have expected, or the care of the wound was starting to impact on day to day living, such as trying to keep dressings dry in the shower, or finding that dressings were leaking onto clothing. Participants reported seeking advice with regards to caring for their wound from health professionals, such as their pharmacist, pharmacy assistant, medical or nursing staff and it is at this point that the trajectory of care begins to diversify.

I asked my daughter what she thought and she kept saying to me that it should be healed by now. There must be something wrong. (P7P5L2-3)

I knew I had to ask someone, so I thought, well I'll ask the girl at the chemist (P15P9L8)

Seeking professional care and advice

Nineteen participants delayed seeking medical treatment for between two weeks and three months, as they were under the illusion that the skin would heal as it had done

in the past. The remaining participant sought medical advice immediately after the onset of the wound, as she had past experience with poor wound healing. When I asked participants why they did not seek medical attention immediately, several reported that they did not feel the wound was ‘bad enough’ (P1P1L10) or did not want to ‘waste anyone’s time over something so trivial’ (P10P1L5). However, as the wound appearance and condition changed or their pain and suffering increased, they sought professional help. The decision to seek advice from a health professional for wound care was made for a variety of reasons including a ‘nagging concern’ (P12P9L4) that the ‘wound should have healed by now’ (P16P8L12), increased pain levels or a ‘crisis’ such as infection.

I had no choice really, I thought it would be OK, but then it started to get really sore and I thought it may have got an infection in it. (P18P3L19)

Several participants reported seeking the advice of a pharmacist with regards to caring for the wound at this initial stage, rather than their Doctor or Nurse. When asked about this decision, participants indicated that they felt more comfortable seeking pharmacy advice, rather than seeking medical or nursing advice.

because they sell the dressings and things so I think they would know a little bit about what to put on. (P7P3L2)

Well it was just easier to go to the chemist and talk to her. I didn’t have to wait for a doctor and it saved me a bit of money, because my Doctor doesn’t bulk bill and the chemist didn’t charge me anything. The chemist came right out and talked to me, had a look at the sore and told me what she thought I should put on. She was very good. When the leg didn’t heal, I went back to her and she said then that I would need to see my doctor, but she at least tried. (P5P3L5-10)

One participant recalled going to her local pharmacy for advice and was referred to a specialist wound clinic as a result.

I went into the chemist to get some dressings and asked the girl if she knew what I could put on them (wounds) to get them to heal up. The girl went and got the

chemist from behind the counter and she took me into a little room to talk to me. I showed her the leg and she said I should go to (specialist wound clinic). I'd never heard of it and I didn't think it was that bad that I needed to see a specialist. She (pharmacist) said to me, look these things can turn very nasty and there are people who specialise in treating them before they get really bad. She gave me the details to take to my Doctor, so that's what I did. I'm glad I did you know. She did me a big favour, because I saw my Doctor and he said 'oh yes I think you should go too' and he gave me a referral. Well I waited about six weeks to get in and the leg was no better. That chemist had given me some dressings to put on but it still wasn't better. It turns out that because the leg was so swollen the sores couldn't heal. Now that I wear the stockings to help the swelling, the sores are getting better. If I hadn't asked the chemist, I don't know where I'd be (P13P4L10-22)

Participants described the initial responses of their health professionals to their wound or wound care, as varying from an attitude of 'minimisation' through to one of concern, depending on each individual's condition. Several participants reported that their health professionals, including Doctors and Nurses, minimised the appearance of the wounds though statements such as 'it doesn't look too bad' (P19P8L7) or 'I've seen worse' (P14P7L18). One participant recalled her nurse examining the wound, stating: 'Oh, it's only small; don't worry too much about it' (P1P8L1). The meaning that the participant attached to this comment was that;

maybe she was trying to make me feel better, I don't know, but it made me feel like it was trivial and I wasn't making a fuss for nothing. I don't care how small it was – it hurt! (P1P8L5-7)

While some participants reported that their health professionals minimised their situation, others reported that their health professionals seemed to take an interest in their concerns from the outset.

My Doctor sat there and listened to me and said, well I think we'll try some antibiotics and I'll send you to (specialist wound clinic) to see what they have to say about it (P10P8L13-14)

My Doctor sent me to (specialist wound clinic) and I know the sore was only little compared to a lot of other peoples but it was just so sore. Well, the nurse there said it doesn't matter if it's small; it was how it was affecting me that was important. It made me feel like I wasn't wasting her time, you know. She really listened and explained things to me so I could understand why it was taking so long to heal up. She made me feel like it was important enough to see someone about and that I wasn't just being a 'sook'. (P1P8L12-17)

One participant recalled seeing her Doctor for the first time and having no personal experience with a chronic wound, stated that she;

put (herself) in his hands. He's the expert. He told me that I needed to put this special dressing on it and he would get the nurse at the clinic to dress it every few days. That went on for about six weeks and it still wasn't healed, even though it was smaller and he said, Oh I think you need to go into (specialist wound clinic), so he made a referral and he rang and spoke to (specialist wound clinic nurse). They got me in pretty quick and now it's nearly healed up. It was good you know because he said I've done what I know how to do and now you need to see someone else. (P11P3L10-15)

Diversity of care

As a result of seeking medical advice and the ongoing, or chronic, nature of the wound healing status, the trajectory of care began to diversify as participants utilised different services for their care. All participants interviewed had been offered a referral to their local District Nursing Service at some stage during their wound journey. For some the initial offer of a referral was declined for various reasons, including work commitments, the decision to undertake their own wound care, or a preference for the wound care to be attended by the General Practitioner and/or practice nurse. For other participants, the District Nursing Service became a routine part of their lives. Of the 20 participants interviewed, one had a referral to the specialist wound clinic after her initial consult with her Doctor and all others were referred to the clinic within 3 months to 60

years after the onset of their wound. At the time of interview, 11 participants received wound care from their local District Nursing Service, five attended their own care and four had their GP and/or practice nurses attending their care. All participants were past or current clients of the specialist wound clinic.

The trajectory of care that follows cannot be described in chronological order, as the processes and events each individual experienced during the trajectory, occur concurrently. This is depicted in diagram 5:1, where 'normal' social, psychological, economical, cultural and environmental influences that impact on every day living, continue to flow through each individuals life, until the onset of a wound. When the wound occurs, participants follow a trajectory that leads them into a life of uncertainty. The trajectory begins with the onset of the wound and is followed by minimisation, the treatments and burdens associated with the physical events of living with a chronic wound, through to the different 'layers' of care received by health professionals. The layers of care consist of individuals receiving wound care from their General practitioner, Practice Nurse, District Nursing Service or Specialist Wound Clinic and often individuals received their care from several services at the same time. Once the point is reached where individuals are receiving differing layers of care, they appear to be caught up in the issues that surround that care, such as the quality of care and advice, which leads them into a life not only of uncertainty, but of turbulence and dissonance.

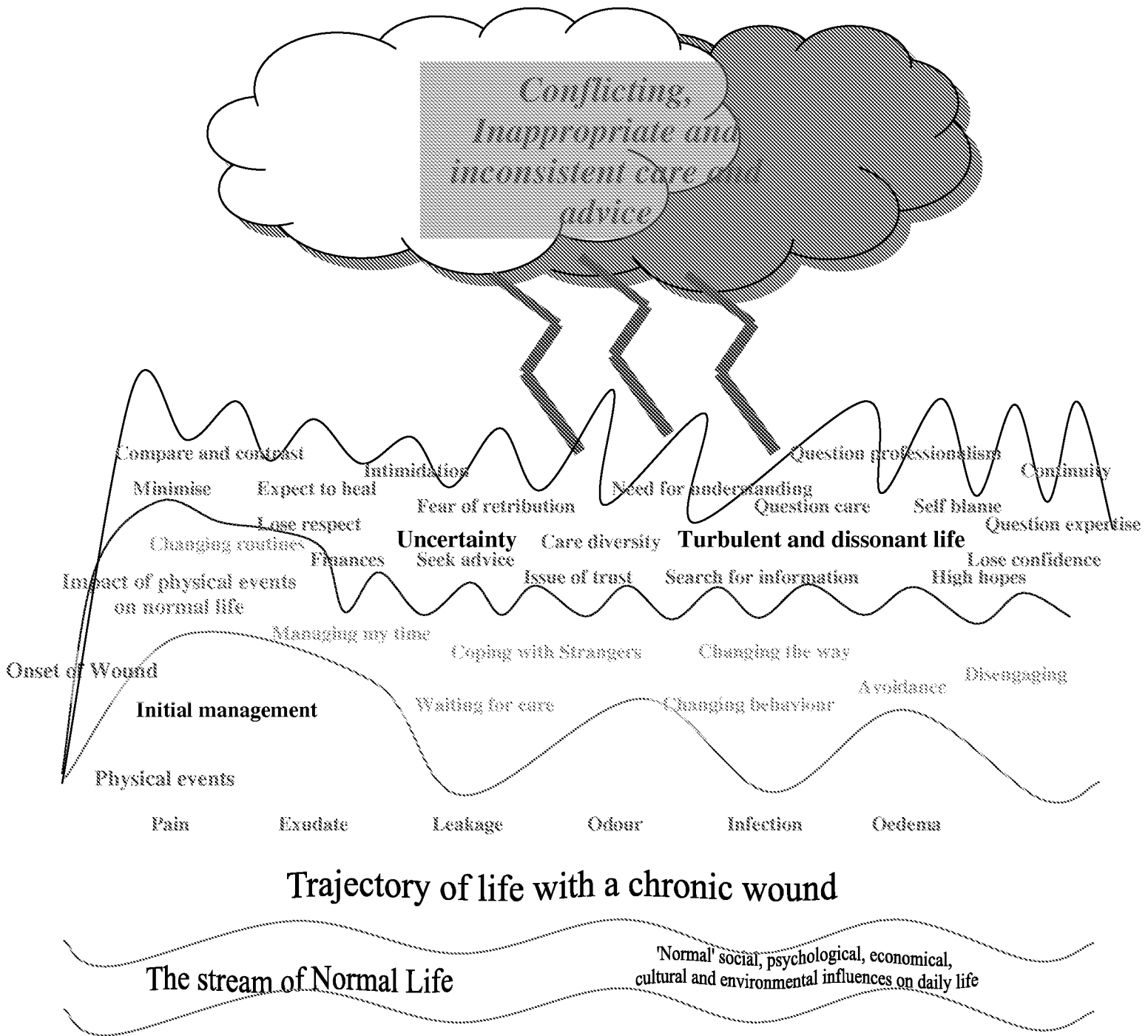


Diagram 5:1 Caught up in the issues associated with a chronic wound and the layers of care that leads to a turbulent and dissonant life

In order to clarify the processes individuals go through when ‘caught up’ in the layers of care and provide a deep understanding of each individual’s experience, I have described these processes within the context of *Layers of Professional Care*.

LAYERS OF PROFESSIONAL CARE

The professional care received by participants came from a variety of sources, including District Nursing, General Practitioners, Practice Nurses, Pharmacist and Specialist Wound Clinic Nursing, Medical and Allied health Professionals. While all participants reported that they were appreciative of the care they were receiving, it became clear to me that the levels of care they were receiving were significantly different. All participants reported receiving conflicting advice, poor continuity of care or inappropriate advice or treatment that was not based on the best available evidence, at some stage in their trajectory of care. As a result, participants described an array of cognitive and psychological processes that were complicated by the layers of care they were receiving from treating health professionals.

CONFLICTING ADVICE AND CARE

One of the most concerning issues to me that was identified by participants, was level of conflicting advice and care they received from health professionals. The conflict that participants described came not only in the form of conflicting advice being offered by various health professionals with regards to wound care, but conflict between the health professionals themselves. Participants who had their care coordinated by specialist wound management services or by senior, experienced health professionals reported less incidence of conflicting advice, than those who had multiple services involved and clear coordination of care was lacking.

CONFLICTING ADVICE

Participants reported conflicting advice as causing frustration and adding to the burdens they experienced with regards to living with a chronic wound. While conflicting advice is an issue that has been identified by Husband (2001), Persoon (2004), Hopkins (2006), and Spilsbury (2007), it is the *impact* of the conflicting advice on the individual that explored in this study. In order to examine the impact that conflicting advice and treatment has on the individual with the chronic wound, the experiences of both appropriate and inappropriate management are explored. In order to gain an insight into their experiences, participants were asked to describe the care and advice that they received during their experience with living with a chronic wound.

Questioning care

When discussing their experiences, all participants described incidents where they received conflicting advice, with the majority reporting that they experienced this on a regular basis. Participants reported that health professionals rarely offered the same or similar advice with regards to the care of their wound. This caused confusion and frustration, to a point where they reported that they no longer knew who to listen to, or which of the advice they were to follow. This caused them to *question their care*.

It's hard when one nurse tells you one thing and other nurse tells you something else and then the doctor tells you something completely different. Who do I believe? Sometimes it makes me wonder whether anyone really knows or understands what's happening (P1P7L6-8)

With everyone telling you something different, who I believe? My Doctor will tell me something, then the nurse tells me something else, then another nurse comes in and tells me something different again. I just wish someone would tell me exactly what's going on and then everyone else do the same thing (P18P7L12 -15)

This issue was further compounded when participants were receiving a variety of professional services, such as General Practitioners, *Practice* Nurses, District Nursing Services and Specialist Wound Clinic staff, or when they were receiving a variety of district nurses visiting their homes.

I get a different nurse every time. One of them will tell me one thing and then a different one comes the next day and tells me something completely different. I can't keep up! (P1P5L11-12)

One nurse told me one thing [dressing] that would heal it and another nurse told me another thing [dressing] that would heal it. I got completely confused and put them both on together and wondered why they looked at me funny! (P15P6L8-10)

I had the (specialist wound clinic) nurse explain to me why the leg wouldn't heal and what dressings we were going to use and it really did make sense. She sent a letter to my other nurses and everyone was following it until one girls said 'oh no that's not right' changed everything. They're both nurses so who was I supposed to believe was the one that was right? I thought they all had the same sort of training. (P8P5L2-6)

Search for Information

In an attempt to make sense of the conflicting advice and information they were receiving, participants reported *searching for information* from a variety of resources including newspapers, books, television, and the Internet. While several participants reported that this helped them to reach a level of understanding where they could cope with what was happening, others reported that it only increased their confusion about their situation. One participant reported reading an article in the local paper

I read in the paper about this bug that gets into you skin and eats your flesh and I thought that's what I had. I realise now that I don't, but it put the wind up me for a little while. After I talked to (specialist wound clinic) and had some tests done, I realise that it's my blood supply and all the smoking I have done hasn't helped (P15P10L6-11)

High hopes

Participants described one of the most frustrating aspects of conflicting advice came from treating health professionals telling them how long their wound would take to heal. There are many factors involved in delayed healing, such as medical co morbidities that affect healing, local factors such as pressure, wound desiccation or blood supply. Each individual tends to heal at a different rate (Carville 2005). For one participant, her recollection of being told the date that the wound would heal, by one of her treating nurses, initially gave her hope and she marked her calendar with the date. When the wound did not heal by this date, she reported that she felt frustrated and ‘a little bit angry’ (P10P13L20), as she had maintained ‘high hopes’ (P10P13L20) for healing by this date and when it didn’t happen, she was ‘annoyed’. (P10P13L20)

I asked the nurse when she thought it would be healed and last year she said it would be healed by Christmas. Well, that came and went and the thing was still there. I pinned hope that when I took the dressing off, it would be gone. She shouldn’t have said anything (P10P13L17-19)

Another participant reported that once she had been given an explanation with regards to why she couldn’t be provided with a specific time frame for wound healing to occur, that the anxiety the expectation to heal within a certain time frame had caused, was relieved.

When I came into (specialist wound clinic) the first time, I found out a lot of things that I didn’t know, but when I asked how long it was going to take (Nurse) told me that because everyone is different and they heal differently and explained the things that happen to make the healing slower, she really couldn’t give me a date when it would heal. I wanted to know when it was going to heal, but I really understood what she was saying and why she couldn’t give me that date. When I went back the second time, she said it looked much better and I didn’t know if she was just saying that, but she showed me a photo and showed me where it was smaller and that made me feel great. I didn’t really need the date anymore, because I knew it was getting smaller and my body would take its own good time!

It's healed now and it healed before I thought it would. I'm over the moon because I've got my life back!' (P16P14L1-10)

Need for understanding

As a result of living with a chronic wound, several participants described needing to understand why the wound was not healing, in order for them to cope with their day to day life. While Edwards (2003) found that individuals did express a 'great interest' to receive information, this study and those of Husband (2001) and Briggs and (Fleming 2007) do not substantiate this. All participants interviewed for this study expressed a need to understand how to manage their chronic wound and the reasons why healing was prolonged.

The district nurses have been great. They explain everything to me, what they doing what they're up putting dressings on and what the dressings are supposed to do. I think it's easier to cope if you understand what's going on instead of wondering all the time (P13P617-20)

I really do feel better when I understand things. For a long time, I wasn't sure what was going on. Now that I understand everything that's involved, I just feel better. More confident you could say. (P15P7L1-2)

When participants received conflicting or inappropriate advice, they reported feeling confused and frustrated as they were not able to understand what was happening.

It made [me] more confused because when they said it was only small and it hurt so much, what was going on? Why won't it get better? I know it's little, but they don't see me in the middle of the night crying in pain. Why don't they understand? Why won't it get better? Sometimes I think they don't know why it hasn't healed (P1P9L1-4)

Self Blame

In an attempt to understand their situation, participants reported *questioning themselves* as to what they were doing wrong, or if they could do something any better to

heal the wound quicker. The anxiety caused by self questioning or blame, was compounded when they received conflicting or inappropriate advice.

I used to spray around the garden and that and I've often wondered, I don't know – I used to wear slacks, but I don't whether they protected me enough. When the nurse said well it might have been that, you know, that caused it, I worried that it was all my fault (P9P1L6-7)

I've had a lot of infections. I feel that I must be slipping somewhere, or I must be dirty or where am I picking it up, or what's causing it if I get an infection. Some nurses tell me to boil the water to clean it; other ones tell me not to. I don't know maybe that's where I get the bug. No one seems to know, that's what makes me think all the time. Worry (P17P8L12-15)

Those participants, who had received appropriate and consistent advice with regards to their delayed wound healing, reported that they no longer felt that they had done something to contribute to their poor healing and were more able to cope with the situation.

At least I know the reason this thing is still there. It's not something that I have done wrong. That's what I used to think, but now I know that it won't heal 'cause the leg is so swollen. I can cope with that because I know once the swelling is under control that things will get better. It's gotten so much better now since I've been coming here (specialist wound clinic) and having these bandages. There's light at the end of the tunnel now (P7P12L7-11)

Issues of Trust

As a result of conflicting advice, it appeared that the *level of trust* placed in the treating health professional was diminished. Participants reported receiving conflicting information with regards to the appearance of the wound and the healing progress. For example, participants described numerous occasions where they had concerns that the wounds were deteriorating as they could see the change in their wound. On voicing their concerns to their treating health professional, they were told that there was nothing to be concerned about. The conflict between the objective and subjective information appeared

to affect the ability of the participants to completely trust what their health professionals were saying to them.

Sometimes I wonder if they're covering something up. The nurses will come and tell me they think it's all right, but I can see the wound myself and sometimes I know it's not all right. Maybe they're covering up or maybe they're just trying to make me feel better, but it does make me wonder and I can't understand what's going on if they don't tell me. I don't know it makes you feel like you just can't trust anyone to tell you the truth (P19P4L3-7)

I couldn't believe it, one nurse tells me one thing and another one comes along and tells me something different. Who on earth am I supposed to listen to? If they can't get their stories straight, how am I supposed to trust them to know what to do? One tells me the leg is better another tells me the next day its not, one tells me this is the right dressing and the other tells me it's not. (P14P3L6-10)

In general participants reported that they believed that a health professional should lead and guide them with regards to wound care, as they believed they had the training and expertise in managing wounds.

I do trust my nurses of course and I think they all know what they're doing to an extent but some nurses are better than others. I guess I trust some of them with looking after me but not so much some of the others (P19P3L12-13)

It seems silly I guess, but I really think that sometimes the nurse or the doctor can't see past their nose! I am putting my trust into them to get this thing fixed, but I wonder you know. Do I trust what they are saying when sometimes they don't even look at the ulcer? (P13P5L6-8)

CONFLICT AMONG PROFESSIONALS

The issues described with regards to conflicting advice from health professionals was further compounded as participants expressed their experience of conflict between health professionals. This not only had an enormous impact on their experience and psychological well being, but appeared to cause them to *question the professionalism* of their treating health professionals.

Questioning professionalism

As a result of conflict between health professional's opinions with regards to wound care, participants reported that they believed the behaviour of some of their treating health professionals was not appropriate. When listening to participants describe their experiences, it was apparent to me that not only was some of the behaviour described inappropriate but was unprofessional and raises significant ethical issues.

It seemed to be every time someone came they had an opinion about someone else who had been or was coming to see me. Sometimes they would ask me who put the dressing on before them and when I told them, they would roll their eyes or say something. It made me feel uncomfortable. (P20P4L13-17)

There's a couple of nurses that come that I don't really like, because all they seem to do is say things about the other nurses that come. It's none of my business and I don't want to hear bad things about the people that are looking after me. (12P6L3-6)

A couple of weeks ago, one nurse told me that the nurse who ordered these dressings didn't have a clue about dressings and she knew better, so she changed it. Like I said if they can't agree on the way things are done, then maybe neither of them have got a clue, but it's me that's left in the middle isn't it? (P14P3L10-13)

The issue of conflict among professionals was highlighted through these comments, where the health professionals openly criticised each other, whereas others experienced the conflict in more indirect methods. One participant who was receiving care from her local district nursing service, specialist wound clinic and general practitioner reported that she was confident with the care she received from the specialist wound clinic and district nursing service because they were;

all doing the same thing. They must talk to each other or something because they all seemed to tell me the same thing and it made me feel really good about things. (P3P3L10-20P3L25-26)

This participant had venous leg ulcers that covered almost the entire circumference of both lower legs. She described being assessed at a specialist wound

clinic and a new regime of wound management had been implemented. Reports of the assessment outcome and management recommendations had been sent to the general practitioner and treating district nursing service. The plan was followed by visiting district nurses. The wounds were starting to heal and the pain level had dramatically reduced according to the participant as a result of the implementation of this regime, which consisted of custom made compression garments being fitted to manage oedema levels in her legs and in turn promoting wound healing. The participant described feeling confident with her treatment, as she could see and feel the results. On visiting her Doctor for a routine review, the Doctor had openly disagreed with her new regime and insisted that she cease this treatment immediately.

I didn't know what to do. I told him about the new treatment and showed him the stockings. He said that he had got a letter from (specialist wound clinic) and he just went red in the face and looked really angry. He took the stockings off and threw them in the bin! I couldn't believe my eyes. He said 'You don't need these things, they are a waste of time and will cut off your circulation' I felt sick in the stomach and wanted to cry because I knew they made me feel better. But he was the Doctor. What could I say? He took all the dressings off and told me that the ointment was not to be used and that I had to soak my legs in a bucket of salt water and leave them open for the air to dry them up. I left there with no dressings on my legs and didn't know what to feel. I couldn't very well argue – he was the Doctor. Well I went home and did what he said and that salt water stung like you wouldn't believe, but I tried to do what he said. The legs weeped and they stuck to the sheets and when I went to get up, they ripped the skin because the sheets were really stuck. I couldn't sleep and I was in so much pain I didn't know what to do. I went back to him the next day and said to him I just can't stand the pain, but he kept saying that this was the best thing to do. Well after that visit that was it. I thought no, it's not the best thing to do, so I went back to the (specialist wound clinic) and I told them what happened and I realised that it was my decision what I had done and what they had done was making me feel better and the legs looked better, so that's what I did. I went back onto the ointment and they made me some new stockings. I felt really bad because he had thrown out the other pair, but they still got me the new ones. I've got a new Doctor now and I will never have to see that other one ever again. The legs are nearly healed and I feel on top of the world. I don't know why I followed what he said. I knew it wasn't right, but I was brought up that way you know. You have to listen to your doctor. They do lots of training and they should know what they are on about. (P3P3L10-20;P4L1-12)

Intimidation and fear of retribution

It was clear from this participant's description, that the impact of the conflict and conflicting advice from treating health professionals had a significant impact on her experience. Unfortunately this type of experience was not an isolated incident, with several other participants reporting similar experiences. When participants were asked why they did not question the directions from their treating health professionals when they felt it was inappropriate, participants reported that they felt intimidated by some health professionals and there was an underlying fear of retribution if they disagreed with them.

You naturally are intimidated, because they are professionals. So I mean you're not going to go and ask the plumber and then do the job yourself, you go to a professional, so you hope they know what they are doing, so you've got to trust them. (P6P5L7-10)

The fear of retribution that participants reported appeared to originate from either past experience or meanings each individual had attached to certain events. Participants reported fearing that if they disagreed or 'went against' the regime their health professional recommended, there may be some form of retribution, such as 'not receiving the best care' (P8P3L12) or 'getting a reputation for not complying with things' (P12P7L4). One participant stated that he felt that if he 'went against' (P15P5L19) his treating health professional, that the health professional would go as far as to no longer attending to his medical needs.

And yet as I say before, you've got to trust your medical professional and if you start going over their head and doing things they don't want you to do they can wipe their hands of you virtually (P10P5L12-14)

One participant recalled regularly attending the Doctor for wound care but had tried some ‘home remedies’ between visits. The Doctor asked her if she had been following directives, as the wound was not improving. She assured the doctor that she was following direction because she ‘didn’t want to get into trouble’ (P18P4L7), knowing that she had actually not followed this advice.

I had tried what he wanted me to do, but it didn’t seem to be working, so I tried a few remedies of my own. I didn’t want to tell him though! (P18P4L9-10)

While most participants could not recall an incident where their fears were substantiated, one participant recalled a surgeon becoming irritated at her when she saw him for advice regarding a wound. As she had previous graft surgery on the same site, it appeared that the surgeon blamed the participant for the breakdown.

Between us, [Surgeon] really went crook at me and [sigh] for knocking it and not looking after it when it was healed and it [the wound] was on the same place. I was carrying the hose and the sprinkler was on it and it [sprinkler] just knocked it [the leg]. It was where he’d done a skin graft on it. It’s not like I meant to do it for heavens sake. (P8P8L4-7)

When this participant was asked how she felt when this happened, she replied that she felt uncomfortable and guilty, even though she knew it was not her fault. On discussing this with her further, it was clear that she believed the behaviour of her surgeon to be unprofessional and inappropriate.

I think it wasn’t called for; what he said. He’s a Doctor for heavens sake. He shouldn’t say things like that. (P8P8L11)

Losing respect

The impact of inappropriate or unprofessional advice appeared to exacerbate the underlying fears associated with living with a chronic wound, such as the fear of amputation. This situation was clearly demonstrated to me when all participants

interviewed stated that they had a fear of amputation at some stage during their wound experience and this fear was exacerbated when health professionals gave not only inappropriate but unprofessional advice that resulted in participants describing a loss of respect for their treating health professional. One such example of this was when a participant described an experience with her nurse, who had been visiting for several months to attend her wound dressings. On attending the dressing after a period of four months, the nurse remarked that the participant may have been ‘better off having her leg off’ (P5P12L4). According to the participant, this comment was made quite ‘flippantly’ and the participant was unsure of how to react. The participant said nothing at the time, but once the nurse left the participant started to cry and remained in this state for several hours. The participant began to fear that this may happen, whereas the thought had never entered her head before.

I couldn’t believe she had said this so casually. I hadn’t really thought about it before but after she said that I could think of nothing else. Turns out that it healed up and I didn’t need to have my leg off and if she hadn’t said anything I probably would never thought of it. I really lost a lot of respect for her after that. (P5P12L10-12)

Another participant told of her experience with her doctor who she consulted with her third episode of leg ulceration in a period of five years. According to this participant, the Doctor joked about her needing her leg amputated.

You just don’t joke about that sort of thing. I never felt the same about him again you know. (P7P6L10)

It is clear to me that if health professionals had looked past the wound and viewed the whole person, casual remarks about amputation would not be made. When recalling other similar experiences with health professionals, participants reported that they

sometimes felt that the health professional was unable to see past the wound and look at the person attached to the wound.

I don't know. The nurses used to come in here and do the dressing and sometimes I had to do it again when they left. The bandage would fall off or sometimes be put on too tight. Sometimes I wondered if I would have been better doing it myself. I've had the thing for years so I know what works and how to put the dressings on so that they will stay. I did try to tell the nurses how to put the dressings on but I felt like I was being bossy so I stopped. I don't think they're realised though that I had a life too. I think they thought that I waited around for them all day but I had shopping to do, my husband to look after, and I had bowls to worry about! Sometimes I felt like they were just there to quickly come in, change the dressing and go without so much as a 'how do you do'. (P5P9L2-10)

She came in and took the dressing off, asked how I was and put another dressing on, then she was gone. Not once did she look at my face, or did she realise that I had not answered her question. (P3P6L13-14) (After making the statement this participant was asked how she felt after this incident and she just shook her head.)

I've had this thing for nearly ten years on and off so I know what works and what doesn't work I tried to tell this one nurse that I was allergic to the dressing she was going to put on but she told me that I couldn't possibly be allergic because it was a new dressing on the market. I told her that I've had this dressing before but she still insisted on putting the dressing on and I had a reaction so bad I had to stay in hospital for an extra week. (P13P7L9-14)

CONFLICTING CARE

Questioning expertise

The lack of consistent information, conflict between health professionals and unprofessional behaviour in conjunction with poor healing, imparted a perception to participants that the treating health professional did not have the expertise they expected.

I have been told so many different things about my wound that I just don't know that what to believe any more it makes it hard to understand why this thing hasn't healed. It makes me wonder if anyone really knows what they're talking about. (P16P6L10-13)

When I went to see the Doctor, firstly he told me it was nothing to worry about and when I told him that I was worried, he looked at me funny, like I shouldn't have been worried. I wondered if he knew anything about these things, because it was really sore. I don't think he would have liked it on his leg. He made it out to be trivial and it just made me wonder if he really knew what he was doing, because he didn't seem to know what sort of dressing to put on or anything (P18P5L14-19)

I had the district nurse come to visit me and I asked her if the leg was supposed to look all green and mucky and she said, oh yes, that's just the dressing doing that. I found out after that it was the bug (bacteria) in the leg that was making that green and I had to put some special ointment on it. It wasn't the dressing at all – she had no idea (P11P2L5-9)

The perception that the health professionals did not have the expected level of expertise to treat participant's wounds was consolidated when health professionals offered advice or treatment that was not based on best available evidence. Participants reported that when they received advice or treatment from a health professional that there was a level of trust on their part, that it would be based on the best available evidence. This did not appear to be the case when listening to participants describe their experiences. One example of this was a participant who was advised by her treating nurse to try a topical preparation on her wound that was indicated for animal use only.

I remember when one nurse told me to try this special cream and she even bought it for me. When I looked at the jar the label said that it was to be used on cows. I asked the nurse about this but she said she had used it before and it worked really well. So I tried it. It was OK for the first day but then it started to burn and made the leg really sore. It ended up burning this skin all around the outside of the ulcer. It turns out I was allergic to something in it. I don't know what, but it had zinc and other stuff in it. I have used zinc before and have never reacted. Maybe I should stick to human things from now on and not listen to people who tell me to use animal ointments! (P5P6L10-18)

Several participants reported that they were advised to leave their wounds open to the air or wash their wounds with vinegar, both practices being contraindicated in contemporary practice (Australian Wound Management Association 2002, Carville 2005).

The nurse said to wash it in vinegar that had been diluted. I could still smell the vinegar a bit but it wasn't strong. My God, when she washed the sore with it, I knew about it! It stung like you wouldn't believe. It got to a stage where I couldn't let her do it anymore, 'cause it just hurt too much (P8P3L10-13)

Losing confidence

Participants further questioned the expertise of treating health professionals when inexperienced health professionals provided their care. Participants reported that although they understood that health professionals needed to undergo 'on the job' training, they felt that it was not appropriate to have untrained staff managing their care. Several participants reported their district nurse bringing other nurses with them to train. Reports indicated that they were confident with this practice, as they felt it was important to have knowledgeable staff caring for them. However when inexperienced staff visited without a more senior supervisor, the participants reported that their *confidence in the care* dramatically reduced.

I remember one of the senior nurses bringing a student or what I thought was a student nurse with them to show them how to dress my wound. The student didn't really know what to do and had to be shown everything which is fine because they need to learn. I was a little surprised to see the student the next day coming to see me on her own. I found out then she was not a student but a new nurse and it didn't make me feel confident in her care knowing that she had only learnt the day before and had no clue as to what to do, let alone if there was a problem would she recognise it? (P1P4L8-15)

Several participants reported being concerned with the care that they received by inexperienced staff, particularly when it came to applying compression bandages. In order to manage lower limb oedema, compression is often used following an appropriate

assessment of the underlying vascular status (Carville 2005). Compression may be in the form of garments or bandaging. The application of bandaging is a learned skill that requires an appropriate level of training and expertise in order to prevent complications such as damage to the tissue. It is important that health professionals prescribing or applying compression are competent in prescription and application technique (Moffatt 1999). Unfortunately, the inappropriate prescription and application of compression was experienced by over half of the participants interviewed. These participants experienced problems associated with their compression, such as discomfort or increased trauma to the skin. These problems occurred as a result of the compression being too high (in tightness), inappropriate bandaging technique, and inconsistency of care or incorrect prescription of garment size or level of compression.

I was having my legs bandaged and every nurse who bandaged did it a different way. One nurse would bandage leaving the heel out, one nurse would bandage with the heel in, one nurse would put it on really tight and another one would put it loose over my foot. It got to a point and when every time the bandage was taken off that the swelling was in a different place. (P12P10L13-16)

And the nurse told me that I needed to have compression bandages put on and put some really tight bandages on me. It started to hurt right up the front after about ten minutes and I didn't know what to do. I tried to put up with that but it just I ached and ached when she finally came back the next day, she took it off and I had sores all up my leg that weren't there before. (P6P10L16-20)

The nurse told me to get some stockings from the chemist so I went in and bought some and they were so tight and so hard to get on, but I got them on. Well I could only stand in for a few hours before the pain got so bad I had to get someone to take them off for me. (P17P15L12-14)

They put these tight bandages on me and left them on for a few days. When they took them off I had sores on my ankles and down my shin from the pressure of the bandage. They told me it was safe. (P14P13L6-7)

While not all participants reported issues associated with wound care or compression as a result of being attended by inexperienced health professionals, all

participants reported receiving conflicting or inappropriate advice or care during their care trajectory.

Care Continuity

The impact of inexperienced health professionals providing care and advice and conflict between health professionals was complicated when participants received a variety of professional services. Participants reported issues with continuity of care, when they rarely saw the same nurse twice. Often the district nurses had never seen the wound before and would ask the participant if they thought the wound was any better, or what they were required to do, to dress the wound. Participants reported that this was extremely frustrating and often left them feeling disappointed or angry especially when nursing notes were in the house and the visiting nurse did not read them.

One of the things that really bothered me was that I never seemed to have the same nurse more than once in a row. Sometimes they would come in and had never seen me before, but instead of looking in the book to find out what to do, they would just ask me. They are professionals and they shouldn't be asking me what to do. They should read the notes. One came in and asked me that if I had been to (specialist wound clinic) and I said, yes I have, there's a letter in there to read. Well she said, 'oh I haven't got time to read letters just tell me what happened'. I said, no you need to read the letter and we almost had an argument. I don't think I needed to do that but she wasn't going to read it and I couldn't remember everything that happened at (specialist wound clinic) That's why they send letters, so I don't have to remember. Well she read it anyway and then she still asked me what to do! (P20P5L8-18)

One thing is you get a different nurse every time. I don't know. How can they tell me its getting better if they've never seen it before? (P1P3L4-5)

My sister said to me it's ridiculous that they seemed a different person every time. How can they know from one day to the next that they're doing the right thing? I agreed with her. It gets so frustrating having different nurses here all the time. (P16P2L14-16)

Continuity of care was also reported as an issue causing frustration and confusion when participants received care from their general practitioner, district nurse or specialist wound clinic and the care was being implemented by a different health professional each time.

I don't know, I go to (specialist wound clinic) and they send a note to the Doctor, but when I go, he either doesn't look at it (wound), or he does it different. Most of the nurses do it sort of the same way but you'll always get one or two who have their own ideas and just do their own thing. I don't see a specialist for the fun of it you know. They know what they're doing and I trust them. Everyone should just do what they've done because when they do it its really comfortable and its healing. (P14P6L10-15)

When listening to this recollection, it was clear to me that coordinated care delivered by senior, experienced health professionals had a positive impact on the trajectory of care and this was reflected throughout the data collected.

Once I had the same person doing the bandaging, things were much better and the ulcer got better too. I just felt like I could cope, you know. Not have to worry all the time about what was coming next. (P10P12L19-21)

After I went to see (specialist wound clinic) they explained why I needed to wear tight stockings and made one especially to fit my leg. I was a bit scared to start with, because the one the chemist gave me hurt so much, but this one was really comfortable. The swelling went down and the leg healed up really quick you know. It took such a load off me to have someone who knew what they were doing. (P1P10L14-17)

Going with the flow

Participants described feeling frustrated and confused as a result of the lack of continuity of care, but at the same time believed that they had no choice but to follow the direction of their treating health professional.

I just go with the flow you know. What can I do. They're the experts and you've got to follow what they say. They know more about treating these things than I do. (P15P9L14-15)

They seem to change things (dressing regimes) a lot and it gets a bit much sometimes, 'cause I can't keep up, but you know you just do what they say.
(P15P9L8-9)

Financial impact

One of the most significant areas of impact reported by participants with regards continuity of care, was the impact of financial burden. While Hildegard (1995), Walshe (1995) Franks and Moffat (1999) and Hyde (1999), have identified the financial burden associated with living with a chronic wound, this study provides an understanding of how conflicting or inappropriate advice and care compounds the financial burden.

According to my experience, the cost of dressings can range from \$1 to \$40 per dressing and can cost anything up to \$100 per week, depending on individual requirements. While there are now limited projects available for home and community care clients (HACC) to access funds for dressings, at the time of interviewing participants for this study, no such funding was available.

Participants cited degrees of financial impact experienced as a result of having a chronic wound. Participants who were on an aged or disability pension described the impact as being more significant than those who were not. The type of dressings and frequency of change impacted on financial concerns, as well as associated costs, such as district nursing services, taking taxis to medical appointments, purchasing clothing to cover the dressings or bandages and purchasing new footwear or compression garments.

It costs me a fortune. I have had to put dressings on my credit card, just so I can have them here for the nurses to use. I am paying anything up to \$100 every time I go to the supply place to get the dressings and when you are on a pension, it really hurts (P4P12L3-5)

Well I only pay \$30 a month for the district nursing; my dressings have gone down now that the ulcer is getting a bit better. I used to be going through 48

nappies around my leg sometimes in a fortnight; well they're \$15/20 for a packet. That's a lot of money when you haven't got it. Sometimes I think it would be better if I didn't have to pay for the nurses to come, but I need them and can't afford not to have them (P14P12L16-20)

In order to cope with the financial strain, participants not only reported feeling angry, but several participants described altering their needs in order to be able to afford their dressings, such as one participant who reported that she made a conscious decision every week regarding what she would 'go without' to pay for her dressings.

I know the dressings are making my leg better, so I can't afford to not have them. If I go without a treat or two, it's not going to be the worst thing that can happen. It probably does me good! (P11P14L6-7)

Another more serious impact was the statement made by another participant who regularly went without groceries to pay for her dressings.

I need the leg to get better, so if I can't afford to get as much at the shops, I won't get them. Sometimes the meat is too dear and if I need dressings or pain killers that week, I'll get something else. My family helps out sometimes with a casserole or something, so I don't really go hungry (P20P15L3-5)

The varying reports of financial impact also revolved around the amount of dressings being used, participants themselves, by the district nursing service or the doctor, when participants were responsible for purchasing their own products.

I always try to watch how much tape I use when I dress the leg, 'cause that stuff can be a bit pricey. I know I can't cut the dressing, 'cause I've tried and it leaked on the first day. If I put a big enough piece on, I can get through anything up to 5 days without having to change it and that's good (P16P15L1-3)

I was a nurse and I remember from my own practice, that I would try to be frugal with how much I used because I don't like to see waste. I watch the nurses that come here and they are so wasteful with the dressings – don't they realise that they are costing me money? I watch them but I don't say anything, I just feel angry inside (P19P16L12-15)

The financial burden was significantly increased when participants received conflicting or inappropriate advice or care. Participants reported difficulties in paying for

their routine dressings and when treating health professionals frequently changed the regimes, the impact was greater.

In the beginning like you've still got your normal household bills to pay and I mean I'm not wealthy and I never married and I had to care for my son. The combines and all that (dressings) were extra. Then they kept changing their minds and I'd have to go out and buy more different dressings. I thought I may as well give them my pension and say 'here divide this up amongst yourselves' (P12P14L17-22)

All the gauze I have bought and all the dressings I have got in my cupboard makes me angry. One nurse or the doctor will tell me to use something and I buy some, use it for a couple of days then someone else will tell me that it's no good and to try something else. I go and buy whatever it is they want and they use that for a week and someone different will tell me something else! Don't they realise how much this is all costing me and how much waste there is. I have a cupboard full of expensive dressings that I can't use!" (P13P15L6-11)

Participants also reported difficulties paying for the more expensive products, even though they stated that they knew that these products would be beneficial to them in the long run.

When I came to (specialist wound clinic), they tried one of those silver dressings and I could see the ulcer getting smaller and smaller. I was really worried about how much it was going to cost, but (nurse) had arranged for the company to give me some trial pieces free of charge. I was using melolin and some gel before that and my bills were around \$30 a month – just one of these dressings was \$28! When we worked it out though, I had this ulcer for about 6 months and it had probably cost me about \$180 for the dressings and \$10 every time I went to see the Doctor which was about once or twice a week. I decided to buy some of the silver and even though it was expensive at first, the ulcer was getting smaller so I wasn't using as much every time. My ulcer healed after a month and I spent \$112 on dressings, had one trip to the Doctor and two trips to the clinic, so it worked out cheaper AND I got the ulcer healed! (P7P15L12-21)

It is clear from participants' reports that the financial strain they experienced as a result of living with a chronic wound was considerable. This was substantially increased when they received inappropriate or conflicting advice or care. While initial outlay was

expensive for some participants, as described in the participants statement above, the long term cost was reduced, as the wound healed in a shorter period of time. The constant changing of dressing regimes and conflicting advice regarding wound care not only impacted on the financial resources of participants, but had the potential to delay wound healing as this practice is contrary to the best available evidence (Carville 2005).

Considering the level of impact experienced by individuals living with chronic wounds, the question is raised, that if individuals were provided with consistent and appropriate advice and care, what affect this would have on the financial burden.

THE IMPACT OF COORDINATED CARE

The coordination of care not only increased the confidence participants had in their care, but also provided an avenue for continuity of care. Participants reported that when they had one person making the recommendations about the wound management and everyone else was following those recommendations, they felt more confident in their care. When participants received a more coordinated approach to their care, their confusion was lessened and participants reported a greater confidence in their care and trust in the treating health professional.

When I went to the specialist wound clinic, they explained everything to me and sent a letter to my Doctor and my nurses so everyone started doing the same thing. If the nurses were worried, they'd ring the clinic and the nurse there told them what to do and they did. Once everyone started telling me the same things and dressing it (the wound) the same, I felt so much better. The ulcer ended up healing – it still took a long time, but we got there in the end. (P20P7L18-23)

When the head nurse (district nursing service) took over my care and told everyone that they had to follow the plan she wrote down, things stated to get better (P8P7L12-13)

I know that it was much easier and I felt better when everyone was doing the same thing. It gave me more confidence in my care knowing that everyone was doing the same thing and saying the same things. (P19P5L16-18)

It just makes sense doesn't it? Its not rocket science that if everyone does the same thing, you will have a better chance (of healing) (P8P5L2-3)

In contrast, when care was coordinated by less experienced staff or staff who had 'decision making' authority and the care was 'controlled' rather than coordinated, participants experienced less confidence, as described by one participant, whose recollection highlights the need for collaborative coordination of care by experienced health professionals.

There was one nurse who said it was her job to do the dressings and no one else was to touch them. She had them scared I think, because even when my dressing was all rolled up and uncomfortable, the other nurses didn't want to change it in case they upset her (P14P2L16-19)

DISCUSSION

It is clear from participant's descriptions that individuals living with a chronic wound experience a life of uncertainty related to the struggle to endure a wounded body and the layers of professional care they receive. When they are provided with conflicting or inappropriate advice and treatment, inconsistencies of care and poor coordination of care, layers of unnecessary burden are added to their experience. The uncertainty and dissonance participants were faced with, leads them to question their care, themselves and the expertise and professionalism of their treating health professionals. As a result, they experienced a loss of respect and trust for their treating health professionals and a loss of confidence in their care. In order to cope with living with a chronic wound, individuals must develop appropriate strategies. Previous authors have identified coping

strategies such as normalising, adapting and self management in relation to living with a chronic wound (Walshe 1995, Douglas 2001, Husband 2001, Hopkins 2004, Ebbeskog 2001), but have not identified the added burden that conflicting or inappropriate advice and care have on these individuals. While it is acknowledged that this study supports previous research with regards to the burdens of living with a chronic wound (Douglas 2001, Rich 2003, Hopkins 2006, Watson-Miller 2006 and Briggs and Fleming 2007), it has identified that individuals living with chronic wounds are receiving inappropriate or conflicting advice and care, which is dramatically impacting on the burdens and the individuals ability to cope with living with a chronic wound.

The impacts experienced by individuals living with chronic wounds can be significantly lessened if they are provided with appropriate and consistent advice and care that is based on the best available evidence that incorporates holistic assessment, management and treatment provided by knowledgeable and experienced health professionals. While this has been identified by Douglas (2001), Ebbeskog (2001), Rich (2003) and Flaherty (2005) as an integral aspect of managing individuals with chronic wounds, it appears from this study, that this is not being transcribed into practice. As a result, individuals living with a chronic wound experience a turbulent and dissonant life that I have likened to *weathering a storm*, which will be discussed further in the next chapter.

CONCLUSION

This chapter has described the impact of living with a chronic wound within the core category of *'The Trajectory of Care'*. Participants' experiences were discussed within the framework of the *initial care* of the wound and *layers of professional care*.

The discussion also explored the impact that conflicting, inappropriate and inconsistent care and advice had each individual and identified the coping strategies they developed in response to that advice and treatment. The experience of individuals living with chronic wounds has been captured in both chapters 4 and 5 and while relating the data and constantly comparing and contrasting within the categories, the substantive theory of *Weathering the Storm of Care*, has been developed. This will be discussed in Chapter 6.

CHAPTER 6

SUBSTANTIVE THEORY: WEATHERING THE STORM OF CARE

INTRODUCTION

This chapter will provide a description of the emergent substantive theory of *Weathering the Storm of Care*, which explains how individuals cope with living with a chronic wound when they are receiving conflicting or inappropriate advice and care. The social phenomenon experienced by participants has been described in chapters 4 and 5, within the context of *Struggling to endure a wounded body* and *The Trajectory of Care*, and this will provide a conclusive description of the substantive theory.

The purpose of this study was to explore and describe the impact that a chronic wound has on the every-day lives of patients who are receiving conflicting or inappropriate care and advice that is not based on the best available evidence, using a grounded theory method. Data collection and analysis occurred simultaneously and the method of constant comparing and contrasting, allowed the extrapolation of social process, provided a direction for theoretical sampling and in turn theoretical saturation and theory development.

The findings of this study at the micro, or local, context clearly illustrate the relationship and connections that exist with the macro, historical contextual level as outlined in Chapter 2.

WEATHERING THE STORM OF CARE

The descriptor of *weathering the storm of care* has been chosen as it provides a description of the cause, consequence and associated social and psychological processes

individuals experience as a result of living with a chronic wound *when they are receiving conflicting or inappropriate advice and care*. The expression of *weathering the storm* alludes to a ship navigating safely through bad weather and I have likened this to the journey individuals experience as a result of the care and advice they receive when living with a chronic wound. In the literal sense of this expression, when faced with a storm, the response is to *avoid bad weather, change direction, and seek shelter and protection*. In the context of this study, participants describe *avoidance* of situations that may result in increased pain or injury, *changing direction* through their search for information and understanding and placing their trust in treating health professionals to *shelter and protect* them, as well as seeking shelter and protection from the advice and care. The substantive theory provides a visual parallel between these events. I have associated the *onset of the storm* as the physical events experienced by participants, the *storm of care* as the conflicting and inappropriate care and advice received by individuals and *weathering the storm of care* as the coping strategies developed in response to the storm.

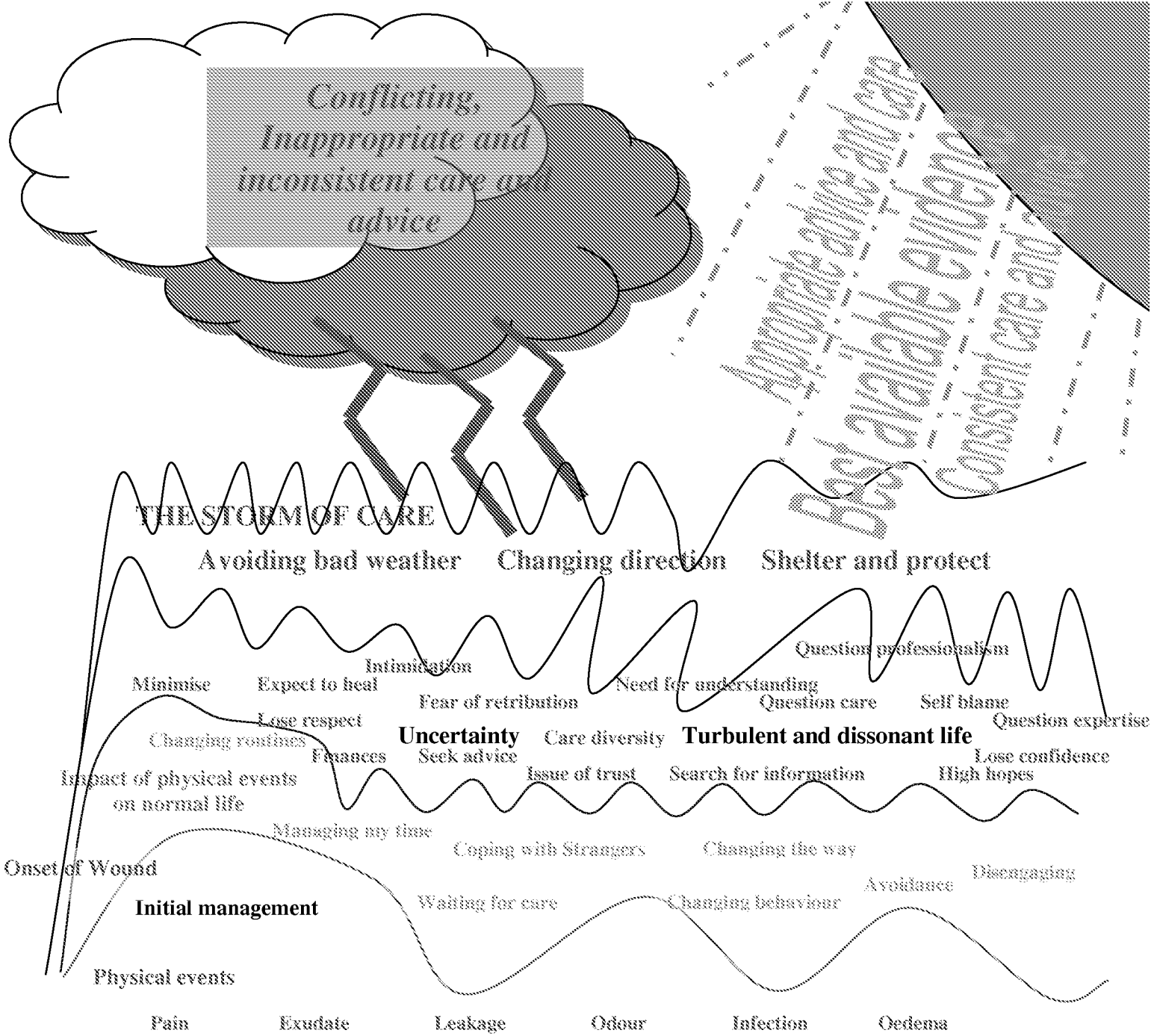
The following discussion provides a revisitation of the social processes described in chapter 4; *Struggling to Endure a Wounded Body* and chapter 5; *The Trajectory of Care*, in order to explain how individuals cope with living with a chronic wound and what impact inappropriate and conflicting advice and care has on their experience. This will provide the context of the emergent substantive theory.

The concept of *weathering the storm of care* contains within it, a beginning point, that is 'normal' life before the wound and flows along a trajectory that is evolving and changing according to the burdens and layers of care experienced by individuals living with chronic wounds. The end point of the trajectory is identified as either complete

wound healing or the point where consistent and appropriate advice and care is provided by experienced and knowledgeable health professionals, that allows the individual to *live* with a chronic wound as opposed to drowning in the burdens and layers of care.

Diagram 6:1 provides a schematic representation of the substantive theory, where individuals living with a chronic wound experience the ‘normal’ social, psychological, economical, cultural and environmental influences flowing through their lives until the onset of the wound. The physical burdens associated with the wound are likened to the onset of the storm and while this narrows the trajectory of ‘normal’ life, it is the inappropriate and conflicting care and advice that causes the turbulence (*Weathering the Storm of Care*) and further impacts on the trajectory of normality. The impact of appropriate and consistent advice that is based on the best available evidence is represented by the sun, which is the end point of the trajectory of care that allows individuals to broaden their trajectory of ‘normal’ life.

Diagram 6:1 *The impact of conflicting and inappropriate care and advice: Weathering the storm.* (Please see page 161)



Trajectory of life with a chronic wound

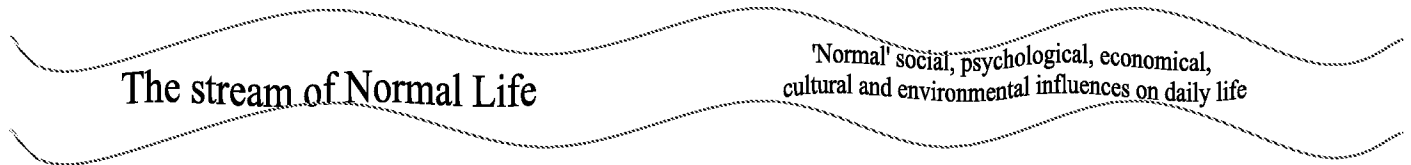


Diagram 6:1 The impact of conflicting and inappropriate care and advice: Weathering

the storm.

THE ONSET OF THE STORM

Twenty individuals living with chronic wounds were interviewed for this study. The experiences they described took me on not only their journey but on a journey of personal and professional discovery. As I listened to their descriptions, it became clear to me that living with a chronic wound was life changing from the onset of the wound. As a result of the physical events associated with the wound, participants described the struggle to endure their wounded body. From their descriptions, I began to associate their journey with one that begins with the 'calmness' of normality and as a result of the onset of the wound and associated burdens, becomes more turbulent according to the level of care, information, expertise and experience of care providers. From the onset of the wound, participants described minimising the initial event and appearance of the wound in an attempt to continue 'normal' life and implemented self management, believing that the wound would heal as it had in the past. Participants described comparing and contrasting their experiences to that of others throughout the wound journey in order to normalise and cope with their situation.

When the wound did not heal the way it was expected to, or a crisis such as pain or infection occurred, the focus shifts from 'normal daily living' combined with simply dressing the wound and minimal suffering, to 'living with a wound'. It is at this point that the storm begins, as individuals experience the impact of physical events such as pain, odour, exudate, infection and oedema. Participants describe a life of pain that impacts on their ability to sleep, mobilise and attend to activities of daily living. The odour and exudate causes embarrassment and discomfort, while infection often results further discomfort and disruption of normal life. Lower limb oedema contributes further

to the physical burdens as participants experience the issues associated with wearing compression. While Flaherty (2005), Walshe (1995), Douglas (2001), Ebbeskog (2001), Rich (2003) and Krasner (1995) have also identified these issues, there is paucity of information available that explores the impact of conflicting or inappropriate advice and treatment. Few studies identified that despite the availability of evidence with regards to the experiences of individuals living with chronic wounds, health professionals are still providing inconsistent treatment and advice to individuals with chronic wounds (Charles 1995; Spilsbury 2007; Watson-Miller 2006; Harding 2002), which may be influencing their ability to develop appropriate coping strategies, but these issues have not been deeply explored until this study.

As the wound becomes more chronic and the impact on day to day life becomes more significant, participants must rely on the services of health professionals for advice and care. While participants received an array of professional care, it is clear from participants' statements that the quality of advice and information provided is widely varied. This has a significant impact on each individual's trajectory of care. As a result of the layers of professional care, participants begin to describe a life of confusion and frustration relating to their care. When they are provided with conflicting or inappropriate care and advice, the confusion and frustration soon turns to turbulence and dissonance as they are often caught up in the conflict.

The Storm of Care

Inappropriate or conflicting advice substantially impacted on each individual's experience. While it is acknowledged that not all individuals living with a chronic wound experience *ongoing* conflicting or inappropriate advice and care, it is concerning that all

participants in this study identified at least one or more occasions where this occurred. Participants described experiences of receiving conflicting advice from their treating health professionals, with regards to their care, the aetiology of their wounds and their ongoing management. The conflicting advice regarding their care and ongoing management revolved around the issues of wound cleansing, dressings and wound healing progress and while health professionals in many instances could not agree on the reason for delayed healing, participants were left wondering. Not only did this cause increasing confusion and frustration for individuals living with the chronic wound, but caused them to question their care and the expertise of their treating health professionals.

When health professionals openly disagreed with the recommendations of their colleagues, participants were caught up in the conflict, not only leaving them feeling uncomfortable, but resulting in a loss of trust and respect for the professionals who were responsible for their care. Further adding to this was the lack of experience and knowledge of some treating health professionals that on occasions resulted in physical injury when a treatment was incorrectly applied. While the provision of inappropriate or conflicting information by health professionals may stem from inexperience and varying levels of expertise in the area of chronic wound management, this issue highlights the need not only for education, but competency standards in this specialist area, for all health professionals treating individuals with chronic wounds.

Adding further to the burdens experienced by individuals living with a chronic wound as a result of conflicting and inappropriate advice and care, is the lack of continuity of care. The ability of participants to cope with living with a chronic wound was compromised when there was a lack of continuity of care. This not only impacted on

their physical ability to heal, but also impacted on their financial burden. Participants described that because so many differing health professionals were providing their care, they no longer knew who was in control or who to believe. It was evident that when the continuity was improved and the care coordinated by a senior experienced health professional the individual with a chronic wound was more able to develop appropriate coping strategies.

In response to conflicting or inappropriate advice and care, individuals living with chronic wounds developed coping strategies that allowed them to *weather the storm of care*. While the strategies they developed enabled them to cope, the question is raised that if they had been provided with appropriate, consistent advice and treatment that was based on the best available evidence, would they have endured such a turbulent and dissonant experience?

WEATHERING THE STORM OF CARE

In the context of this study, participants describe *avoidance* of situations that may result in increased pain or injury, *changing direction* through their search for information and understanding and placing their trust in treating health professionals to *shelter and protect* them as well as seeking their own shelter and protection.

Avoiding bad weather

In the context of *weathering the storm of care*, participants described changing their behaviour or routines to avoid the physical events associated with living with a chronic wound. Participants described disengaging from social activity and interaction as a result of physical events and the psychological turmoil caused by embarrassing odours or leakage from dressings. As a result of pain, participants described the sleep

deprivation, reduced mobility and a reduction in the ability to attend to activities of daily living. In order to cope with these issues individuals described changing their routine such as avoiding shopping centres during busier times or no longer participating in hobbies such as gardening for fear of injury or re-injury.

Changing direction

As the impact of wound chronicity increased, participants attempted to weather the storm of care by *changing the direction* of their care. In essence, individuals attempted to change what was happening by seeking information, understanding and alternative treatments.

When they had become aware that the wound was not healing as they would normally have expected, or the care of the wound was starting to impact on day to day living, individuals relied on their experiential knowledge, trying different strategies. Such strategies included positional changes or sleeping in a chair to cope with pain, or seeking alternative dressings, such as vegemite or bleach to heal their wounds. This led to participants seeking professional assistance for wound care from health professionals, such as their Pharmacist, Pharmacy assistant, Medical or Nursing staff and it is at this point that the trajectory of care began to diversify. Individuals described receiving a plethora of conflicting advice from both lay persons and health professionals that was a constant source of confusion and frustration. Douglas (2001), Hopkins (2006), Spilsbury (2007), Husband (2001), Persoon (2004), Walshe (1995), Watson-Miller (2006) and Charles (1995) have also identified that the provision of conflicting advice and treatment could cause frustration, confusion, anger, fear and anxiety for the patient, but they did not

explore the impact on the individuals ability to cope with living with a chronic wound that resulted.

When the advice and information provided by health professionals was conflicting or inappropriate, participants began to question the care of their treating health professionals and sought information from a variety of sources, such as family and friends, the Internet or local newspaper articles. This further contributed to their confusion, frustration and anxiety, as often the information was not based on the best available evidence.

Participants also described a need to understand their situation and why their wound was not healing. When they were in receipt of conflicting or inappropriate advice, this need was not met. In order to meet their needs, participants continued to search for information and in an attempt to change course and make sense of their situation, often blamed themselves for what was happening. This level of self blame further increased the anxiety participants described, which could have been allayed with appropriate and consistent advice and information.

Shelter and Protect

In order to shelter and protect themselves, participants continued to seek the advice of health professionals, but in doing so found that they also needed to shelter and protect themselves from the advice and care of the treating health professional.

In order to protect themselves from injury or re injury, participants described employing methods such as avoidance behaviour and disengagement, as have been previously described. On seeking advice from health professionals on how to both treat their wounds and cope with their situation, participants reported that several health

professionals offered advice that was both appropriate and consistent. However, there were many more health professionals who either did not agree with that advice, did not implement planned treatment regimes or their care lacked continuity and coordination. Participants were exposed to conflicting or inappropriate advice and care that was not always consistent or based on the best available evidence and individuals found themselves seeking shelter and protection from those who were responsible for their care. Participants described losing trust in their treating health professionals' ability to care for their wound. This not only led them further into the turbulence, but resulted in individuals questioning the expertise of their treating health professionals. The issue of trust was further compromised when care was provided by inexperienced health professionals and led participants to question the expertise of their treating health professionals. Walshe (1995), Rich (2003) and Husband (2001) have identified that wound care must be based on best practice and delivered by health professionals who are knowledgeable in the field and participants expected a level of expertise, that their care would be based on the best available evidence. This did not appear to be the case when listening to participants describe their experiences.

The issue of conflict between health professionals that was identified by participants has not previously been identified in the literature reviewed for this study. This issue was of significant concern as this experience not only impacted on the individuals' ability to cope with living with a chronic wound, but reflected a lack of professionalism that not only compromised care but raised significant ethical issues. The conflict among health professionals brings into question the professionalism of treating health care providers and resulted in participants losing respect for those who were caring

for them. The conflict was intimidating to participants, who felt fearful that if they questioned their care or the advice of the health professional, that their care would be compromised.

While participants were describing the strategies and tactics they found necessary to employ in *weathering the storm* of care, it was clear to me that when they were provided with consistent, appropriate care and advice that was based on the best available evidence, the potential to alleviate the burdens was substantial. As a consequence, the necessity to *avoid bad weather, change direction* and *shelter and protect themselves* may no longer be inevitable.

When provided with appropriate, consistent advice and care that was based on the best available evidence, participants described a feeling of relief and hope, were less confused and regained confidence in their care and trust in their treating health professionals.

In order to alleviate the burdens associated with conflicting or inappropriate advice and care, it is vital to provide individuals with appropriate, consistent care that is based on the best available evidence. It appears that if each individual with a chronic wound is provided with appropriate, evidence based information that focuses on the individual as a whole, as they have indeed done in some services such as the specialist wound clinic, there is a significant potential to alleviate the added confusion, anxiety and frustration experienced by participants.

Health professionals must take into account the social and psychological processes each individual goes through when faced with living with a chronic wound. Individuals faced with chronic wounds expect their wounds to heal and in order to fulfill

that expectation: individuals will draw on experiential knowledge, seek advice and search for understanding. It is the responsibility of health care providers to increase the awareness of the individual with a chronic wound regarding the processes involved in wounds becoming chronic, the importance of early intervention and evidenced based practice. It is also the responsibility of health care providers to maintain a high level of competency with regards to chronic wound management in order to be able to continue to provide individuals with chronic wounds with the most appropriate and evidence based information and treatment. There is evidence available that provides an insight into the experiences of individuals with chronic wounds and clinical practice guidelines that recommend holistic assessment and management of individuals with chronic wounds. (Flaherty 2005; Walshe 1995; Douglas 2001; Ebbeskog 2001; Rich 2003; Krasner 1995). However it appears from the results of this study, that this evidence is not being transferred into practice

Health professionals who do not approach an individual from a holistic perspective are not only neglecting their duty of care but substantially impact on the experience and journey each individual goes through. It is clear that appropriate and consistent information, advice and care, that is based on the best available evidence, that is delivered by experienced and knowledgeable health professionals, has the potential to significantly reduce the impact on the lives of individuals living with chronic wounds.

CONCLUSION

This chapter has provided a description of the emergent substantive theory of *Weathering the Storm of Care*, which explained how individuals cope with living with a

chronic wound when they are receiving conflicting or inappropriate advice and care. The physical events experienced by participants were described in the context of the *onset of the storm*, the conflicting and inappropriate care and advice received by individuals within the *storm of care* and the coping strategies developed in response to the storm were described in the context of *weathering the storm of care*. The social phenomenon experienced by participants described in chapters 4 and 5, within the context of *Struggling to endure a wounded body* and *The Trajectory of Care*, provided a conclusive description of the substantive theory.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

INTRODUCTION

This chapter will provided a summary of the study by revisiting the original aims and objectives of the research. From this, recommendations for nursing practice and education are made.

RESEARCH AIM

Using a grounded theory approach, the key aims of this study were twofold:

- to explore and describe the impact that a chronic wound has on the every-day lives of patients.
- to generate a theory explaining how individuals cope with living with a chronic wound.

Achievement of aims

The impact of living with a chronic wound appeared to equate to a major life changing event, as individuals experience the burdens associated with a wounded body and the trajectory of care. Compounding this burden was the provision of inappropriate or conflicting advice and treatment by health professionals. This study has explored the impact that a chronic wound has on the every-day lives of patients and has identified the impact of advice and care. The impact has been described within the context of *Struggling to endure a wounded body* and *the Trajectory of Care*.

A substantive theory *Weathering the Storm of Care* has been generated. This theory explained how individuals cope with living with a chronic wound when they are receiving consistent professional health care and the impact when health care

professionals are not providing consistent care based on the best available evidence. This theory described individuals living with a chronic wound, who were receiving conflicting or inappropriate advice and care in the context of the *onset of the storm*, that described the physical events experienced by participants. The *storm of care* described the conflicting and inappropriate care and advice received by individuals and *weathering the storm of care* described the coping strategies developed in response to the storm. The coping strategies were described in the context of *avoiding bad weather, changing direction, and seeking shelter and protection*.

This study identified that individuals living with chronic wounds are being provided with inconsistent advice and care that is often conflicting inappropriate, is not based on the best available evidence or is provided by inexperienced health professionals. Conflict among health professionals was also identified and raised a significant concern with regards to both professionalism and ethics. The impact on individuals living with chronic wounds was significant, as they faced living in a turbulent and dissonant world that was further compromised as a result of the provision of conflicting or inappropriate advice and care.

When provided with appropriate, consistent advice and care that was based on the best available evidence, participants described a feeling of relief and hope, were less confused and regained confidence in their care and trust in their treating health professionals. It is clear that appropriate and consistent information, advice and care, that is based on the best available evidence, that is delivered by experienced and knowledgeable health professionals, has the potential to significantly reduce the impact on the lives of individuals living with chronic wounds.

RECOMMENDATIONS

In light of the findings of this research, the following recommendations are made:

1. To incorporate the findings of this study into existing wound care programs, through liaison with wound care education providers.
2. To incorporate the findings of this study into the Australian Wound Management Association Standards for wound management with regards to the provision of appropriate and consistent advice and care that is delivered by experienced and knowledgeable health professionals.
3. To use the findings of this research to facilitate discussions with all health professionals responsible for treating individuals with chronic wounds regarding the provision of appropriate and consistent advice and care that is delivered by experienced and knowledgeable health professionals and the impact of inappropriate advice and information.
4. To use the findings of this study to facilitate discussions with health professionals to highlight to issues of conflict between health professionals and the impact this has on those individuals whose care they are responsible for through dissemination of results through journal publication and conference presentation.
5. To use the findings of this research to facilitate discussions with all health professionals responsible for treating individuals with chronic wounds to ensure that all individuals with chronic wounds are provided with appropriate advice and care that is consistent and based on the best available evidence. This will be achieved through publication of results, conference presentation and liaison with education providers.

6. To continue to build on existing education services for health professionals treating individuals with chronic wounds in order for them to be able to provide appropriate and consistent advice and care that is based on the best available evidence.
7. To ensure holistic chronic wound assessment management education modules are incorporated into all nursing and Medical training through universities and further education facilities.
8. Increase the profile of specialist wound management services, develop processes to ensure early access to service and build on existing education services to ensure that health professionals treating individuals with chronic wounds have access to a variety of training modalities, in order to ensure that individuals living with chronic wounds are not only provided with assessment and management based on best practice, but that care is provided by competent and experienced health professionals. This can be achieved through marketing of existing services, the establishment of a regional wound resource group in conjunction with the Australian Wound management association and the establishment of a National directory of specialist wound management services.
9. To use the findings of this research to facilitate Government funding for specialist wound management clinics to provide best practice management and education services and to establish financial assistance schemes to assist individuals with financial costs.

10. To use the findings of this study to develop models of care that address the issues identified by participants in this study, in the management of individuals with chronic wounds.
11. To generate an interest in further studies to explore why, with the level of knowledge and expertise that exists in the area of wound management, that individuals with chronic wounds continue to experience conflicting or inconsistent treatment and advice, when there are a variety of specialist services readily available to support contemporary practice?

It is the intention that the findings of this study will be disseminated at state conference level and through national publication. It is also envisaged that the findings of this study will contribute to provide impetus for further research and education in the management of individuals with chronic wounds.

CONCLUSION

This chapter has provided a summary of the study by revisiting the original aims and objectives of the research. In light of the findings of this study, recommendations for nursing practice, research and education have been made in order to alleviate the burdens experienced by individuals living with chronic wounds that are created by conflicting or inappropriate advice and care that is not based on the best available evidence.

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APPENDICES

Appendix 1	Ethics approval: RMIT Human Research Ethics Committee
Appendix 2	Ethics approval: Bendigo Health Human Research Ethics Committee
Appendix 3	RMIT Human Ethics Research Committee consent form
Appendix 4	Plain language statement

Appendix 1: RMIT HREC approval



SCHOOL OF LIFE SCIENCES

23rd July 2002

Andrea Minnis
Department of Nursing and Midwifery
715 Melbourn Highway
Sunshine VIC 3551

Dear Andrea,

FLSAPP 15 – 02 MINNIS The impact of Chronic wounds.

Thank you for submitting your application for consideration by the Faculty Subcommittee of the Human Research Ethics Committee of RMIT University.

Your application was considered at the meeting 06-2002 on Wednesday July 3rd, 2002 and an extract of the minutes is included below for your information.

The committee noted the ethical issues as:

1. Informed consent
2. Confidentiality
3. Vulnerability
4. Dependant Relationships (between investigator and potential participant)

Pursuant to discussion the committee noted:

1. HREC must receive a copy of the approval from the Health Care Group Ethics Committee.
2. Q2 – Provide name of the facility where research is being undertaken
3. Need to address the words 'vulnerability' and 'dependancy' separately when discussing chronic wound patients.
4. Need to clearly state what the relationship between investigator and participants is.
5. Checklist is legible, need to check items by hand.
6. PLS: Clearly state that current research may not directly benefit participant.
7. Inconsistency in confidentiality statements. Re-word to state that the participant will not be identified in any way.
8. Citations are made however there are no references listed.
9. Data retention section F3. Timeframe should be amended from seven years to five years.
10. The committee would like to commend the applicant for a well-argued proposal.

The Committee considers this to be a Minimal Risk proposal and that it is appropriate to be approved provisionally for a period of 2 years to August 2004, subject to amendments of the points listed to the satisfaction

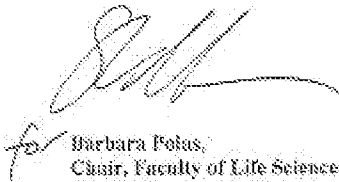
Appendix 1 (cont)

of one of the Committee members. Once the points have been attended to would you please submit two clear copies, one to the Chair and one to Dr. Peter Obendorf (ext 57136)

A formal letter of approval will not be forwarded until amendments have been received. Research may not begin until approval has been given.

Once you have met these requirements you will receive confirmation that you can commence your research.

Yours sincerely,



Barbara Polas,
Chair, Faculty of Life Sciences
Faculty Sub-committee of the HREC

cc: Prof. Olga Kanitsaki
Dr. Peter Obendorf

Appendix 1 (cont)



0421 9475 7188

11 September 2002

Andreas Minnis
735 Melvor Highway
Jarratton VIC 3551

Faculty of Life Sciences

Bond Street Campus
Building 201, Level 2, Bond St
Melbourne
Business School
Victoria Australia

PO Box 245
Bundoora 3083
Victoria Australia

tel: +61 3 9325 7188
fax: +61 3 9345 7098
<http://www.lifesci.rmit.edu.au>

Dear Andrea,

FLSAPP 15-02 MINNIS The impact of Chronic wounds.

Thank you for submitting your amended application for review.

Please note that the committee stresses that the participants in your study are dependent because the investigator is also their nurse. The participants in this study are also vulnerable because they have chronic wounds.

Your application also needs to be signed by the Dean of the Faculty of Life Sciences, as the Head of Department is also your supervisor.

Once you have attended to the proper signing of this proposal I will be in a position to approve your application for a period 2 years to August 2004. Your research may then proceed.

The committee would like to remind you that annual reports are due during December for all research projects that have been approved by the Faculty Human Research Ethics Committee.

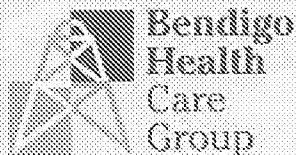
The necessary form can be found at:
www.rmit.edu/departments/secretariat/hrec/html

Yours faithfully,

Barbara Polus
Chair, Faculty Human Research Ethics Sub-Committee
Faculty of Life Sciences

cc: Prof Olga Kanitsaki

Appendix 2: Bendigo Health HREC approval



CONFIDENTIAL

Acute hospital
Aged care
Rehabilitation
Psychiatric care
Palliative care
Community support
Health promotion

18/01/2002 14:55:02

PO Box 126
Bendigo 3552

Human Research Ethics Committee
Phone: (053) 5454 6439
Fax: (053) 5454 6430

Monday, 9 September 2002

Ms Andrea Minnis
John Lindell Rehabilitation Unit
Bendigo Health Care Group
P.O. Box 126
Bendigo, Victoria, 3552

Dear Ms Minnis

Re: Study Title: The Impact of Chronic Wounds

HREC Reference Number: 15/2002

I am pleased to advise you that the Human Research Ethics Committee of the Bendigo Health Care Group has approved the above project.

The project has been approved for the period 9/9/2002 to 30/9/2005.

Would you please note that the following standard conditions apply:


- Limit of Approval:* approval is limited strictly to the research proposal as submitted in your application.
- Deviation to Project:* any subsequent variations or modifications you might wish to make to your project must be notified formally to the committee for further consideration and approval. If the committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.
- Incidents of Adverse Effects:* researchers must report immediately to the committee anything which might affect the ethical acceptance of the protocol including adverse effects on subjects or unforeseen events that might affect continued ethical acceptability of the project.
- Progress Reporting:* please be aware that the Human Research Ethics Committee requires all researchers to submit a report on each of their projects yearly, or at the conclusion of the project if it continues for less than a year. Failure to submit a progress report may mean approval for this project will lapse. The first progress report for this project is due on 9/9/2003.
- Auditing:* all projects may be subject to audit by members of the committee.

If you have any further queries on these matters, or require additional information, please contact me on 5454 6419, or e-mail: mrc@bendigohealth.org.au. Human Research Ethics Committee information and ethics documentation is now available on the Bendigo Health Care Group Intranet (local access only) at http://bhcgwabi/Committees/Human_Research_Ethics/Details.html.

Please quote the HREC reference number and the title of the project in any future correspondence.

On behalf of the committee, I wish you well in your research.

Yours Sincerely


Michael Orlenzani
Secretary
Human Research Ethics Committee
Bendigo Health Care Group

Appendix 3: Consent form

HREC Form No 2b

RMIT HUMAN RESEARCH ETHICS COMMITTEE

Prescribed Consent Form For Persons Participating in Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

FACULTY OF

DEPARTMENT OF

Nursing and Midwifery

Name of participant:

Project Title:

The Impact of Chronic Wounds.

Name(s) of investigator: (1)

Andrea M.B. Minnik

Phone:

54548500

(2)

Phone:

1. I have received a statement explaining the interview/questionnaire involved in this project.
2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.
3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.
4. I acknowledge that:
 - (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.
 - (b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.
 - (c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.
 - (d) The confidentiality of the information I provide will be safeguarded. However should information of a confidential nature need to be disclosed for moral, clinical or legal reasons, I will be given an opportunity to negotiate the terms of this disclosure.
 - (e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to _____ (specify as appropriate). Any information which will identify me will not be used.

Participant's Consent

Name:

(Participant)

Date:

Name:

(Witness to signature)

Date:

Where participant is under 18 years of age:

I consent to the participation of _____ in the above project.

Signature:

(1)

(2)

(Signatures of parents or guardians)

Date:

Name:

(Witness to signature)

Date:

Participants should be given a photocopy of this consent form after it has been signed.

Any complaints about your participation in this project may be directed to the Secretary, RMIT Human Research Ethics Committee.

Appendix 4: Plain language statement



Research & Innovation

Attachment 1. Plain Language Statement

Faculty of Health Sciences

Dear

*Sundown West Campus
PO Box 77
Sundown 2033
New South Wales
Tel: +61 8 9028 2432
Fax: +61 8 9067 1629*

I would like to invite you to participate in a study I am undertaking as part of a Masters of Nursing by Research Degree through the RMIT University.

I am seeking your permission to collect information about how your wound has affected your life. If you agree to participate, you will be required to sign an informed consent form before taking part in this study.

Aim

The aim of collecting this information is to explore the challenges you face because of your wound. While the outcome of this research may not benefit you directly, I am hoping that the information will assist nurses and other health professionals to understand and provide 'best practice management' when caring for you and your wound.

How will the information be collected?

I will arrange a time which suits you and I, so that we may sit down and discuss how your life is affected by having a chronic wound. This interview will be arranged to coincide with your normal review appointment, so that you do not have to make an extra visit to the clinic and will take up an extra hour of your time.

The information will be collected by talking to you about your life and how having a chronic wound has affected your life, if at all. I will tape record the things you say and will analyse this information after you have left. I will listen to what you have said through headphones, in order that no one else will hear our conversation. I may also take notes during our conversation to record what I am thinking.

Will my name or other identifying details be recorded?

No.

You will not be identified in any way and the information written down and tape recorded will be locked securely away at all times when I am not using them and I will be the only person who has access to the information.

All information that identifies you will remain confidential. Information will be identified by number only. This number will be randomly allocated at the commencement of the project. I will keep a record of identification numbers in a password protected computer program and will be the only person with access to this password. The code numbers allocated will not be included in standard medical records.

No names, addresses or other forms of identification will be accessible to anyone other myself, unless that information is part of the standard medical record. Information pertaining directly to the study will not be included in the standard medical record.

What will happen to this information?

Once the study has been completed, the results analysed and the study has been passed as a Master Thesis, the intent is to publish the results in a journal. The results will be presented to the study setting and may also be presented at a conference. Any presentations or publications will be in a form such as to protect your anonymity and you will not be identified in the final report to be written up from the research. Information collected will be held in a secure location until such time as the final report is

Appendix 4: Plain language statement (cont)

complete and for a period of 7 years thereafter. This information will include the tape recorded conversations and notes taken during the interviews.

Consent

You should not feel pressured into participating in this information collection process and should feel free to decline this invitation at any time. Your care and treatment at the clinic will not be affected in any way should you decline to participate. Should you decide to participate, you will be required to sign a consent form. You may withdraw from information collection process at any time without this affecting your care and treatment at the clinic. Please take your time to make this decision and feel free to discuss this with your family, friends or general practitioner (GP). Should any further information be required, or should you, or your family, friends or GP wish to discuss this invitation further, please do not hesitate to contact me. You are invited to seek further information regarding this project at any time.

Regards,

Andrea M.B. Minnis RN Div1, Grad Dip H.Sc, Cert Ger Nursing, MRCNA
Clinical Nurse Consultant
Tissue Trauma Clinic
Telephone: (03) 54548500

Any complaints about your participation in this project may be directed to the secretary, RMIT Human Research Ethics Committee, University Secretariat, RMIT, GPO Box 2476V, Melbourne, 3001. The telephone number is (03) 99251745.