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Linda Louise Husband

Managing chronic illness: the personal experience and the professional management of venous ulceration

Submitted in 1996 for the degree of Doctor of Philosophy
Department of Sociology and Social Policy

This thesis explores the personal experiences of those who have venous ulcers and examines the ways in which health professionals manage their care. Most patients expect that a consultation with their doctor will lead either to a cure or a plan of care that will minimise the impact of the disease. Those who seek medical assistance because of leg ulcers achieve neither. Instead of diagnosing the type of ulcer and prescribing specific treatment, the general practitioner defines the wound simply as a "leg ulcer" before referring the patient to a nurse for ongoing care. In this situation where the cause needs to be known in order to give direction to nursing management problems arise directly from this lack of precision.

It is not a nursing function to determine the medical diagnosis and the nurse lacks the professional preparation to assume this extended role. However, because of custom and practice and a belief that she has more competence in this area of care than her medical colleagues, the nurse attempts to do so. She focuses on the ulcer rather than on the effects of the disease on the patient and as a result she fails to meet his nursing needs.

The patient's personal narrative is used as diagnostically significant information rather than as the basis for nursing care. Consequently, his quality of life suffers due to ineffectively treated pain and anxiety born of a lack of information. Moreover, he experiences considerable difficulty in presenting himself within his social setting because of the interventions chosen to deal with his venous ulcer. The goals and the needs of the patient which should be at the core of the health provision become secondary to the diagnostic quest of the nurse.

With heartfelt thanks to Robin Williams for his expert supervision and encouragement and for helping to turn an academic dream into a reality.

and

With gratitude to Margaret Willis for her sustained support and interest and for showing me the purpose of research and teaching in nursing.

**Managing Chronic Illness: The Personal Experience and the Professional
Management of Venous Ulceration**

Linda Louise Husband

submitted for the degree of Doctor of Philosophy

University of Durham

Department of Sociology and Social Policy

1996



13 JAN 1997

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Chapter 1 Introduction and overview

This thesis is concerned with the experiences of people who have venous ulcers and their management by health care professionals. Before presenting an overview of the research findings and detailing the structure of the remainder of the thesis, a brief introduction to chronic illness will be given. Venous ulceration represents the most obvious sign of a chronic condition known as venous hypertension. For those who develop these wounds, life becomes complicated particularly because of the acute care approaches taken to their care. This mismatch of intervention strategy is a problem for all who suffer from long term incurable health problems but, as will be seen, it is accentuated for those with venous ulcers because they are handled in such an anomalous way within the health care system. The nature of chronic illness and the approaches to its management provide the context of this study.

The chronic illness perspective

“Chronic illness is a condition that is a much larger problem in Europe than is often realized. About one person in ten lives with a chronic illness or disability and, with the rapidly growing number of the very old, this proportion is increasing”(Asval, 1992, ix).

Chronic illness, by definition involves the:

“irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability”(Lubkin, 1990, p.6).

In these situations a cure is not possible and interventions and adaptations directed towards palliation and the normalisation of the patient's life are required. However, one of the greatest barriers to the effective management of chronic illnesses and the improvement of the care of the individuals who live with them, is the fact that the interventions and therapies applied to them were designed for the treatment of acute illnesses.

“This means, on the one hand, that the symptoms of the illness are treated instead of the person, and on the other, that the treatment aims only at curing instead of focusing on how to help the patient live with a long lasting illness” (Pott, 1992, xi).

This approach presents considerable problems for the individual sufferer. When the role of the doctor is one of "recasting the illness in terms of theories of disorder" and in reconfiguring illness problems "as narrow technical issues" and as "disease problems...something essential to the experience of chronic illness is lost" (Kleinman, 1988, p.5-6). It matters greatly to the patient with a chronic condition, that his experience is translated into scientific accounts and measurements of disease. The failure to appreciate the differences between the disease and the illness as experienced affect the patient at every level. From the onset of symptoms the person seeks meaning. Faced with professionals who work under the assumptions of Cartesian dualism, the patient is, from the start, disadvantaged. To the individual, his symptoms are the "mind's subjective interpretation of the body's real disease experience." (Benner and Wrubel, 1989, p.195) but to the professional, they are merely indicators that may or may not reflect actual pathology and truth. The weight placed upon the objectively discernible "signs" indicates to the patient that his experience is assessed against an external standard and that when a discrepancy occurs, the objective will be held to be true. This approach has profound effects on the patient because when symptoms are regarded "as legitimate only if they are the result of disease (it) means that the patient requires a license for suffering" (Benner and Wrubel, 1989, p.196). Bury (1988) has coined the term "meanings at risk" to describe the situation of potential conflict between the individual and others, including health professionals, when the personal significance and definition of symptoms may be disputed. In many cases, a discrepancy in interpretation is the source of much personal suffering and social disruption. As the person searches for congruency of meaning or for the diagnostic label that will legitimise his assertions of illness and confirm his perceptions of bodily experience, much self doubt and conflict can be engendered. This situation is seen clearly in the case of many patients who have a slowly emerging chronic illness. The patients with multiple sclerosis who were studied by Stewart and Sullivan (1982) took, on average, five and a half years to obtain an accurate medical diagnosis. The period before diagnosis was a time when significant others doubted the patient's perception, when he was labelled as neurotic or anxious

or viewed in a similarly unfavorable light. In the same way, the stories of those with arthritis who were interviewed by Bury (1988) illustrate the difficulties faced by patients and families when symptom presentation is either misinterpreted by the doctors or, the doctors, knowing the diagnosis with certainty, choose to employ a "gradual dawning" (p. 101) approach in order to avoid confronting a patient with potentially serious and upsetting information. Achieving an accurate diagnosis was a source of relief for many patients who were then able to leave the confusing period of uncertainty behind them and obtain acceptance of their views from their families and friends.

This period of uncertainty and of "meanings at risk" may be found whenever a chronic disease unfolds slowly over time and the full biological picture has yet to emerge with clarity. The health services are not particularly adept at dealing with people in this transitional phase. The limitations of technology and of medical understanding of disease onset might prevent an appreciation of the patient's story of the lived experience and it is important to appreciate that the biomedical model is essentially reductionist in nature and therefore quite simply and deliberately, tends to neglect the social and psychological factors associated with the illness experience. The emphasis in medicine on cure rather than on care negates personal experience which cannot be quantified objectively.

The current provision of health care does not adequately address the needs of people who suffer from chronic illnesses. The pattern of medical practice that developed and perhaps suited a period when acute diseases were the main threat to a society, is no longer appropriate. The success of modern medicine has contributed to a substantial degree to the levels of chronic illness so prevalent in our society. With the introduction of antibiotics and the development of drugs to treat diabetes and hypertension, with new technology that supports patients with kidney failure, and allows new surgical techniques such as open heart methods to become commonplace, the health care system has been transformed and medical and nursing specialties have evolved as a result. The specialties that developed, such as the intensive care and the high dependency units and the clinics devoted to particular illnesses, are now an

accepted part of acute care hospitals (Strauss and Corbin, 1988, p.22). With their advent, however, came the dependence upon the acute care approach to illness management in which the patient as a whole person can so easily be lost. The emphasis in acute care settings on the biological aspects of disease is intentional but it is not meant to be the sole focus. Some nurses and doctors attempt to care for their patients holistically within the acute care framework and to ensure that social and psychological issues are not overlooked. Unfortunately, the demands of the acute service approach mean that, in many instances, the desired goal is never realised due to the pressures of the work load, the lack of preparation of the nurses for teaching, and the medical organisation of care that allows patients to be precipitously discharged from the hospital to the home without time for the teaching that might safeguard their health status in the community setting (Tilley et al., 1987, p.293-296). Similarly, a patient treated as an "outpatient" may move from one clinic session to another, and be cared for by a number of nurses who deliver the required technical care, but who do not appreciate his worries, concerns, or his needs for information and health teaching simply because these are not core acute care concerns.

Chronic diseases intrude into the lives of the sufferers and the disruption caused by them is compounded by their medical management and the organization of care. The patient, used to conforming to the pattern of acute care provision where short term dependence upon health professionals often reaps the reward of cure, is also expected to comply with the medicalisation of his chronic disorder, where his acceptance of the imposed regimen makes normalisation increasingly difficult. In the end, the patient's social environment may become effectively manipulated so that it is a professionally managed milieu. This view was expressed by Friedson (1970) who went on to emphasise the essential flaw in this approach:

"It is important to bear in mind that such a round of life is *not* organized by the disease and the biological incapacity it may produce but by professional conceptions of the disease and of what is needed to treat it: the disease becomes a professionally organized illness" (p.310-122).

The care required from the professionals becomes never ending and ultimately, the views of the professionals come to dominate those of all others concerned because they structure the care, control the information, and transmit their vision to the patient within a relationship that is essentially unequal in power. Even within the primary care setting, the patient deals with health care personnel who have been trained or educated predominantly in acute care institutions and who may well continue to value that approach. Whereas, post registration training may give increased knowledge concerning chronic illnesses it may do so in a very medically oriented manner and it is certainly no guarantee of a more equal relationship or of a better understanding of the impact of the illness on the individual. A review of the nursing literature on chronic care by Hinton-Walker(1993, p.57), for example, indicates that there is "much more written about the impact of *disease* than on the general nursing care for chronically ill people, regardless of the disease or age." This finding will be borne out by any one who searches the literature on chronic illness; there are very few books that cover the subject and the vast majority do so from the standpoint of the pathology, both physical and psychological. The impact of the symptoms, the personal meanings, the biographical disruption, the ways in which normality is threatened by the onset and progress of a chronic illness are overlooked in favour of what might be described as a more clinical approach.

It is into this context that the patient and his family must come when they seek diagnosis, clarification, access to services, access to medication and care for the problem of venous ulceration. The health service personnel might adapt to assist them but to do so appropriately, they would need to gain insight into the lives of those with chronic illnesses. Used to intervening in the acute phases of a chronic illness and to dealing with the perhaps "technical" aspects of care on a short term basis, doctors and nurses may have little exposure to the real lives of their patients lived outside health care facilities. Chronic illness is not a matter of acute episodes scattered into an otherwise normal life but rather, it is a matter of total readjustment of an individual's and his family's lifestyle to accommodate the illness experience and its management within a

biography. Strauss and his colleagues(1984, p.7) argue that because of the nature of chronic illness, the wider issues of patient care, that is the social and psychological aspects, must be addressed in addition to the medical facts. Successful management of care for these patients is only possible when it is based on an understanding of the reciprocal impact of the illness experience and disease management. To those who would argue that the medical and nursing staff are indeed aware of these wider issues, Strauss and his colleagues reply simply that they were not and that the organisation of health services makes the personnel accountable for “medical and procedural actions, not particularly for those pertaining to psychological and social matters—witness the charting and reporting”(p.9).

The chronic illness trajectory framework

The chronic illness trajectory framework developed by Corbin and Strauss(1992) is the conceptual model that was chosen for this study. It has two main purposes: to sensitise the researcher to the substantive area and to help in the analysis of the data. Although it will be presented in detail later in the thesis, the central features will be introduced here to assist in the initial discussion of the personal experience of those with venous ulcers and their professional management .

The central concept of the model is that of trajectory, that is, the course of the illness and the work required during it as well as the impact of that work on all concerned (Strauss et al. 1984, p. 64). The course has direction and shape. The course of any trajectory is linked to many people and factors: a knowledgeable nurse and doctor, for example, could help the patient to regain lost functions, while those with less skill might cause actual harm and deterioration. The patient and his family are also shapers of the trajectory and their ability to help will influence the nature of the trajectory.

Trajectories begin when signs and symptoms are present. There is a pretrajectory period before the disease begins when prevention may be possible. Of significance is the role of the nurse within this framework: she gives “supportive assistance”, that is, she helps the individual to shape his

illness course while maintaining his quality of life (Corbin and Strauss, 1992, p. 22-23). Her involvement with the patient is directed to very specific ends. It is not her role or function to take control or management from the patient but to assist him in making specific goals and in enacting agreed plans that will minimise the impact of the illness on his biography during the various phases of his illness experience. It is a framework that places the patient in the key position and makes everything and everyone else peripheral to him. It allows the important features of the individual's life and the reciprocal impact of the illness and treatment to be brought to the foreground because it places the illness within his unique biography.

Focus of the study

This study examines the experiences of people who had been categorised as having "venous ulcers" and it explores the approaches to their management taken by doctors and nurses. The pathology of venous ulceration involves a breakdown of the skin of the lower limb:

"caused by an abnormality of the veins draining the limb. There is no single venous abnormality that is always associated with ulceration. A venous ulcer is usually situated in the gaiter region of the leg and is invariably surrounded by thickened, pigmented and fibrotic skin which we have called lipodermatosclerosis" (Browse, Burnand and Thomas, 1988, p. 349).

It is the most obvious result of the condition termed venous hypertension in which the pressure within the veins of the lower leg is, for some reason, abnormally elevated. Venous disorders are common in western countries and encompass such conditions as varicose veins and deep vein thrombosis. Raised venous pressure from any source may lead to venous ulceration and it does so in approximately 1% of the population. There are no surgical remedies available to restore function to the venous systems of most of the sufferers and for the majority, the onset of ulceration marks the beginning of an illness experience that will remain with them or recur for the rest of their lives.

This research focuses on the exploration of the issues of relevance to those who have venous ulcers and those who manage their care. It adopts a

symbolic interactionist perspective which seems most clearly to illustrate the processes inherent in chronic illness care. As Blumer (1962, p.183) asserts, individual behaviour "is not a result of such things as environmental pressures, stimuli, motives and ideas, but arises instead from how he interprets and handles these things in the action he is constructing." The interpretations of experiences made by patients and their carers give a rich and meaningful picture and allow the researcher to develop a theory of their experience that is grounded in their understanding.

That this area of patient experience and health care management has not previously been examined from this perspective highlights the importance of the present study. The majority of previous studies have dealt simply with venous ulcers, that is, with the physical pathology and its management and have largely ignored the lives of the sufferers. There is, however, an appreciation shown in the medical, but non-research, literature that the experience of having a venous ulcer is unpleasant, disruptive, intrusive and the source of psychological morbidity:

"Ulcers are often painful and smelly. They require frequent dressings and visits to or by medical personnel. They therefore interfere with work and holidays and restrict the lifestyle of the patient. As a result patients with this problem may develop personality disorders, even severe depression and paranoia.

The patients' daily life may come to revolve around the ulcer and it may provide the only reason for contact with the inhabitants of the world outside the home for a depressed, aged and immobile patient...Bathing is a problem when the leg is wrapped with dressings making it difficult to maintain personal hygiene. This may add to the sense of isolation...

An inability to stay at work because of frequent visits to the doctor or the hospital may inflict a considerable economic burden on the patient. The cost of drugs, dressings and elastic stockings is an additional financial burden. All these factors make venous ulceration a miserable experience which is the reason why so many patients are so grateful when their doctor shows some enthusiasm and interest in their care"(Browse, Burnand and Thomas, 1988, p.412).

However, a research based understanding of the experiences of those with ulcers and the approaches of their carers is only very slowly emerging.

Only when the condition is understood as the patients experience it will nursing be able to respond appropriately to their needs.

Management of care

The management of the care for these patients will be seen to be very unusual in a number of respects. In most other chronic conditions, such as hypertension, asthma, or diabetes, the daily care of the symptoms is returned to the patient after an period of diagnosis, stabilisation of the pathology and also of patient education. That is, the professionals will *pilot* the patient through a particularly problematic or acute phase of illness and then return full *navigational* control to him. This approach is essential if any degree of normalisation is to return to the individual's life because the illness must be incorporated as part of and not be allowed to remain the focus of a person's life. In the case of most patients with venous ulcers, however, the care is never returned to them because the nursing staff responsible for their management treat the ulcer as an acute medical problem and introduce treatments so complex that they require nursing care. Given that these ulcers may remain open, despite treatment, for many years, this approach seems both ill advised and inordinately intrusive.

Patients are very used to dealing with their health related problems in their everyday lives and they have skills and expertise in chronic illness management that the professionals lack. As a result, the professionals, trained in acute settings, often need help from the patients to translate regimens into the context of a life lived in the community. Doctors and nurses are not the key carers, or "workers" in chronic illness: the individual and his family and friends are and any attempt to influence the course of an illness must take into account their strengths and weaknesses, their resources in terms of understanding, money, equipment, health and time. The focus of the health professional on the disease often conflicts with that of the individual who wishes to accommodate the illness within the background of his life. This difference can lead to conflict and to behaviour that the professionals might term "noncompliance".

When the able and competent individual enters the doctor's surgery requesting help for a distressing symptom of ulceration, however, he usually leaves as a patient from whom all responsibility for ongoing care has been at the very least, temporarily stripped. The basic social process of navigating, that is, of directing one's own life, making decisions, solving problems, is the process that leads the individual to consult after a period of unsuccessful self treatment. What he seeks in consultation with his doctor is a professional pilot, that is, an expert who will assume temporary and very limited control of his health trajectory in order to restore him to health. In almost every other situation when an individual seeks a pilot, the person selected is someone employed by the individual and the relationship between navigator and pilot is clearly defined with the power skewed in favour of the navigator. In health situations, however, this is often not the case. Attendance at a surgery entails the assumption of a passive attitude that might be reasonable in an acute illness in order to affect a cure and resume navigating speedily. The patient reasonably assumes that he has an acute problem. When he is sent by the doctor to see the nurse, he accepts that direction as he would any other prescription. In doing so, he loses his navigational role slowly and often without awareness that his role has changed. It is usually only after considerable time has elapsed that he realises that his situation is one of chronic illness and his treatment is perhaps totally outside his control.

Not all patients lose their navigational role, but most certainly do. This role is taken from them by nurses who often fail to see the implications of their actions and who may come to resent the reactions of their patients which they may think indicates a "lack of compliance". However, there are also some examples of nurses who have a greater appreciation of the patients' right to be included in decision making and many nurses in this study indicated that they attempted to provide symptom control and made efforts, not necessarily effective, to minimise the effects of the ulcer on their patients.

The relationship that a patient with a chronic illness has with his nurse is usually a long term one. Contact may have been made on a daily or perhaps weekly basis for years. Despite the duration of the association there are

surprisingly few patients who have sufficient knowledge to play a truly equal part in care; patient teaching is only considered in certain situations and these indicate a bias against the patient group. The lack of patient teaching is associated with a lack of definition of the problem by the nurses. In any other condition, a patient, on consultation with his doctor, would be given an accurate medical diagnosis, or, failing that, at least a tentative one to guide treatment while further investigations were carried out. In the cases of patients who present themselves with ulcers, however, the doctors merely give prescriptions to deal with the most obvious of symptoms and then refer the patients to the nurse. It falls to the nurse to determine the nature of the underlying pathology; that is, to establish a medical diagnosis. This situation is perhaps unique in primary care and it has important implications for the well-being of the patient and for the professional practice of nursing and medicine. The abnormal nursing role instigated by the doctor and accepted by the nurse, is the basis of precarious trajectory management in which the patient relies almost totally on the nurse: the nurse assumes a navigating function in relation to the patient's health trajectory. When the nurse oversteps this boundary and assumes control of care, when she mistakes a chronic wound for an acute health problem, and focusing on the most obvious sign of pathology fails to hear the patient, then her patient is not simply disadvantaged within the health care system, his biography becomes disrupted in ways no chronic illness could be expected to achieve. It is in understanding the concerns of all involved in the management of "venous ulcers" and in hearing their voices directly and not filtered through the agendas of quantitative researchers that health care can be improved and the patients' lives can be normalised most effectively. In the end, the picture that emerges gives insight into the present situation and also enables a view of what "grounded caring" would entail for this patient group.

Structure of the thesis

Chapter 2. The condition of venous ulceration

In order to place this particular health problem in context an overview of the prevalence and patterns of its expression and management is given. There

follows a very brief description of the types of leg ulcers and the importance of accurate diagnosis. Information about the financial and personal costs of ulcer management concludes this introductory section.

The anatomical and physiological structures and functions that maintain normal venous pressure in the lower limb are then described and illustrated in order to give further background to the study. Primary and secondary prevention of venous hypertension are then discussed and the essential causes of venous hypertension are introduced in detail. As the most obvious effects of venous ulceration are seen in the skin, this organ is described and the normal mechanism of wound healing is presented. This information provides the necessary background on which to describe the various theories of causation of the signs and symptoms of venous ulceration. This section is followed by a discussion of the implications for management that arise from the anatomy and physiology.

Chapter 3 The chronic illness trajectory framework.

The trajectory framework is a substantive theory of chronic illness "developed specifically to provide insight and knowledge about chronic conditions in general" (Corbin and Strauss 1992, p. 10). It was used by the researcher as a sensitising framework that assisted in the expansion beyond the limitations of nursing and biomedical models. The concepts of the model were found to be useful in analysing and exploring the data from this study and the findings are later presented with reference to them.

Following an historic overview of its development, a general introduction to the trajectory framework is given. The nursing model as developed by Corbin and Strauss (1992) is then presented and its applicability to the practice of nursing in a variety of chronic illnesses is discussed with reference to specific critiques by a number of specialist nurses. Modifications to the trajectory framework are suggested by the researcher as a result of this analysis.

Chapter 4 Methodology

This study used the grounded theory method developed by Glaser and Strauss(1967). The rationale for this choice of approach is given and then followed by a brief introduction to grounded theory in both philosophical and historical perspective. A description of the method is then given and followed by a discussion of how the method was applied to this study.

Chapter 5 Presentation and analysis of the findings

This lengthy chapter is subdivided into six sections. Section A, *Introduction: shaping the illness experience*, deals with an introduction to shaping in illness and presents the core category of *navigating* and the allied process of *piloting* in detail. The phases of personal and professional navigating are discussed and this material is illustrated diagrammatically to indicate how navigating and piloting would be seen in both acute and chronic illness.

Section B, *Personal navigating in venous ulceration*, explores the process of lay shaping as it is seen in the phases of *solo navigating*, *navigating by network*, and *navigating by consulting a pilot*. The perceived seriousness of the individual's condition is covered in the context of his signs and symptoms, the possibility of containment and the problems of uncertainty and the influences of others within his network. This section ends with the decision to seek a professional pilot.

Section C, *Professional piloting: the general practitioner's role*, analyses the purpose of the clinical encounter between a doctor and his patient. The centrality of medical diagnosis is emphasised and the recommended medical management of the patient is contrasted with the actual management. The universal abdication of medical responsibility for making the medical diagnosis is then discussed based upon the literature from the United States of America, Canada, Australia and Britain.

Section D, *Professional navigating: nurse shaping*, presents the findings regarding the organisation of nursing care for patients with venous ulcers and

examines the legitimacy of the diagnostic role they assume in relation to these patients. The educational background of the nurses involved with these patients is discussed.

Section E *The attitudes of the professional carers and their impact on patients*. This section examines the attitudes of the nursing and medical staff towards the patient group and explores the level of ageism discovered. The impact of the approaches of the staff on the patients are considered.

Section F, *Reciprocal impact: part 1, Pain and professional deafness, part 2: Hidden anxieties and disordered lives*. Part 1 examines in detail the problem with pain that the patients with venous ulcers experience and it explores reasons for the professional deafness of the nurses caring for them. The nurses' focus on the wound and the need to determine the underlying pathology contrasts sharply with the patients' focus on biography and pain. In part 2, the obstacles to normalising presented by the management of care by the nurses form the basis of discussion. The nurses' treatment choices and care routines, and the lack of health education necessitate considerable information and normalisation work on the part of the patients.

Chapter 6: Conclusions and implications. This chapter summarises the core issues and problems illuminated by the study. The implications for medicine, for nursing and for the public are presented and discussed. "Grounded caring" in the context of venous ulceration is presented and discussed from the patients' perspective to conclude this study.

Chapter 2: The condition of venous ulceration

The problem in context: prevalence, expression and management

Venous ulceration represents the final stage of a pathological process. It begins in a number of ways: with an often silent deep vein thrombosis which leaves the patient unaware that damage has occurred, with varicose veins that progress to the extent of destroying the effectiveness of the valves, with direct trauma to the veins or from lack of mobility of the ankle joint which in turn prevents the normal physiological reduction of venous pressure within the lower leg. There is a continuum of venous disorder and whereas the prevalence of mild varicose veins in a western population is approximately 45%, venous ulceration affects only 1% of the general population at some point in their lives (Kamber et al. 1978, p.43). That 1% however, is not insignificant in terms of the number of people affected, the cost of care to the National Health Service, nor the suffering to the individuals involved.

There have been a small number of recent surveys of the prevalence of leg ulceration in Britain. Among the most important are the Lothian and Forth Valley Survey (Callam et al., 1985) and a study in the Harrow Health District (Cornwall et al., 1986). In both studies, the prevalence, that is, the existing number of cases in a population at a given time, was found to be similar. The Lothian and Forth Valley study found a prevalence of 1.5/1000 in the total population, which increased to 3.8/1000 in those aged over 40 years, and in the Harrow study, the rate of 1.8/1000 in the population overall, rose to 3.8/1000 in those aged over 40 years. In both surveys, only those with active ulceration and not merely a history of leg ulceration were included. This approach gave a "point prevalence", that is, a rate for the period of the study. The figures of overall prevalence of the condition as opposed to the experience of ulceration, indicate that at any one time only 20-25% of ulcers are "active", or, open (Dale et al., 1983, p.310). From these figures it was possible for the researchers to extrapolate to the population of the United Kingdom and suggest that there would be, approximately, 100,000 patients with open ulcers at any one time "drawn from a population with leg ulcers of 400,000" (Callam et al. 1985, p.1856).

The Lothian and Forth Valley survey was the most significant study of leg ulceration ever to be undertaken, covering a population of about one million people and examining not only the extent of the problem but also identifying the nature of the underlying pathology and gathering data on the provision of care. Callam and his colleagues identified a total of 1,477 people with chronic leg ulcers and in a follow up study (1987a) examined 600 of those in detail in order to determine their clinical condition and history. Given below are their key findings relating to age and sex distribution.

Age	Women	Men	Total Number
20-29	1	1	2
30-39	2	5	7
40-49	17	15	32
50-59	54	30	84
60-69	103	54	157
70-79	144	52	196
80-89	92	14	106
90-99	14	2	16
Total number	427	173	600

Table 1. Age and sex of patients with leg ulcers.

Source: Callam M J, Harper D R, Dale J J, Ruckley C V (1987a) p.1390.

From these figures, it can be seen that the experience of leg ulceration is predominately a female experience and a condition that is present more in the older age groups. However, an examination of the figures below of the age at onset of ulceration, indicates that is a condition that occurs at most ages and that up to the age of thirty, the distribution is almost even between the sexes. The economic consequences in terms of prescription charges and possible time lost from work for those of pre-retirement age begin to be appreciated when it is noted that of the people identified as having “active” ulcers at the time of the survey “just under half of the men and one quarter of the women” were in this category (Callam et al., 1985, p.1856).

	Women	Men	Total
10-19	8	6	14
20-29	23	21	44
30-39	65	22	87
40-49	64	26	90
50-59	77	34	111
60-69	82	36	118
70-79	70	24	94
80-89	32	4	36
90-99	6	0	6
Total Number	427	173	600

Table 2. Age at onset of leg ulceration

Source: Callam M J, Harper D R, Dale J J, Ruckley C V (1987a) p.1390.

The following graph shows the duration of the "current ulcer" at the time of the study and from this data the personal impact on the patient begins to be seen; the majority of people who develop an ulcer take between one and five years to achieve healing.

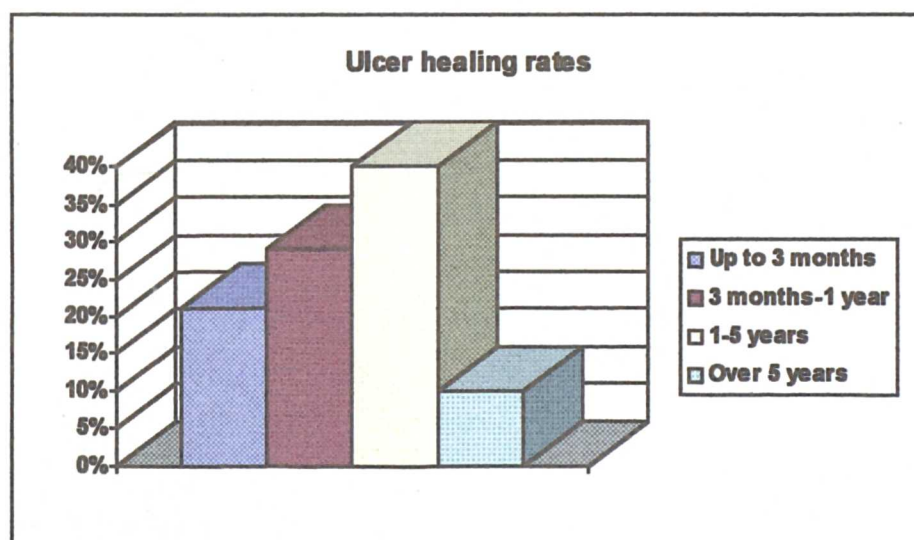


Figure 1. Ulcer healing rates

Source: Lothian and Forth Valley Study(Dale and Gibson 1986, p. 215)

It is important to note that the above diagram shows the duration of the ulcer present, that is "active", at the time of the study. It is the fortunate individual who experiences only one ulcer and figure 2 illustrates the recurrent nature of the problem.

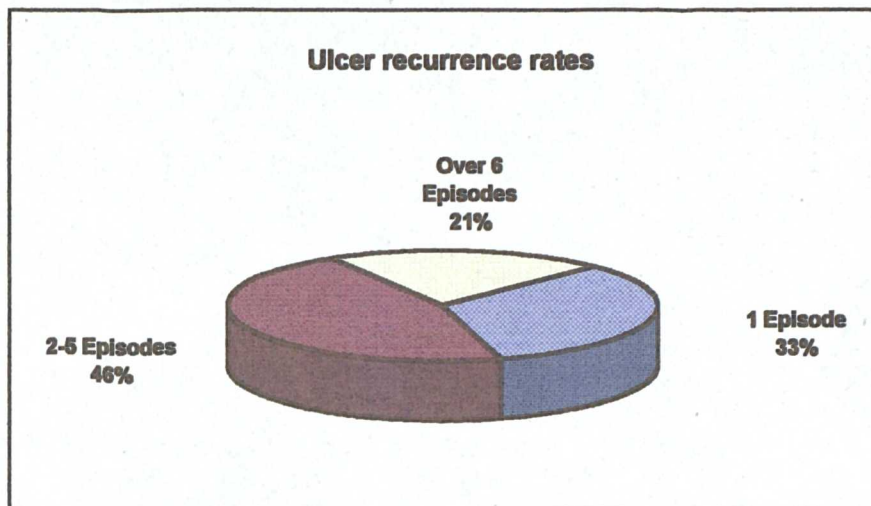


Figure 2. Ulcer recurrence rates

Source: Lothian and Forth Valley Study (Dale and Gibson, 1986, p.215).

The figures so far given refer to patients with leg ulcers and not solely to those with venous ulcers. Callam and his colleagues (1987a) in their follow up study examined a sample of 600 patients from the 1,477 initially identified as having "leg ulcers". They found that the patients had a total of 827 ulcerated legs and assessment with doppler ultrasound indicated that in 21% there was a significant involvement of the arterial system. Arterial involvement was positively correlated with age and reached a level of 50% "in the very elderly"(Callam et al, 1987b, p.930). This was a notable finding because it had been widely accepted up to that time, that venous ulcers were by far the most common form of leg ulceration occurring in between 70-90% of all patients (Browse, Burnand and Thomas. 1988, p. 372). The table below shows the causes of ulceration and their expected frequency of occurrence.

Venous insufficiency	70-90%
Arterial insufficiency	5-20%
Rheumatoid arthritis	5%
Trauma	2%
Neoplastic change	1%
Others	2-0.5%

Table 3 The causes of ulceration and expected occurrence rates.

Source: Browse, Burnand and Thomas (1988), p.372.

The finding that a greater than expected number of patients with leg ulcers were suffering from significant arterial disease was supported by the study of Cornwall and her colleagues in the Harrow Health District (Cornwall et al., 1986). In their study population of 198,900 people, 357 were found to have leg ulcers. Examination of a random sample of one hundred of this number showed an ischaemic element was present as the sole pathology in 9% and was combined with venous disease in a further 22% giving a total figure of 31%.

The importance of medical diagnosis

Accurate medical diagnosis is an essential element of care for patients with a leg ulcer for two main reasons: first to guide the trajectory management of those who have an essentially chronic condition and to minimise disruption to their lives, and secondly to determine which of the patients could benefit from surgical correction of their underlying pathology. Arterial grafts might be used to improve blood flow in some patients and the stripping of the saphenous vein and the perforator veins could remove the cause of venous hypertension in approximately twenty-five percent of patients with ulcers of venous origin (Sethia and Darke, 1984, Negus and Friedgood, 1983). Failure to identify those patients who have pathology amenable to surgical correction sentences them to the ongoing experience of painful wounds and disrupted biographies.

Similarly, failure to determine the pathology responsible for the chronic wounds in all other cases produces a situation in which inappropriate and

potentially dangerous management of those patients is possible. The treatment required by each of the main types of ulcer is totally different in focus: venous ulcers are treated with some level of compression bandaging to redress the increased venous pressure but arterial ulcers or venous ulcers complicated with significant arterial compromise require measures to increase the blood flow to the limb. If an arterial ulcer is, in error, treated with the levels of compression commonly used to alleviate the effects of venous hypertension, the end result can and has in many cases been amputation (Ruckley et al. 1982, p.615-616).

The costs of care

Although it is assumed that there are people who manage their ulcers completely without professional help, the number is considered to be small and most people are thought to request professional care at some point. The majority of patients with leg ulcers are managed in the community with the help of either a District or a Practice Nurse. Callam and his colleagues (1985, p.1856) found that in the Lothian and Forth Valley area, 87% of patients were cared for primarily by community staff, leaving only 13% in the care of hospital personnel. In the Harrow study, (Cornwall et al., 1986) 62% were found to have been managed entirely in the community and after an initial consultation with the general practitioner, the care of these patients was managed by the District Nurse.

The frequency of treatment varies and the percentage of nursing time absorbed by this area of care has only recently received attention. The number of visits undertaken by the District Nurses was ascertained by the researchers in the Lothian and Forth Valley study and is illustrated below:

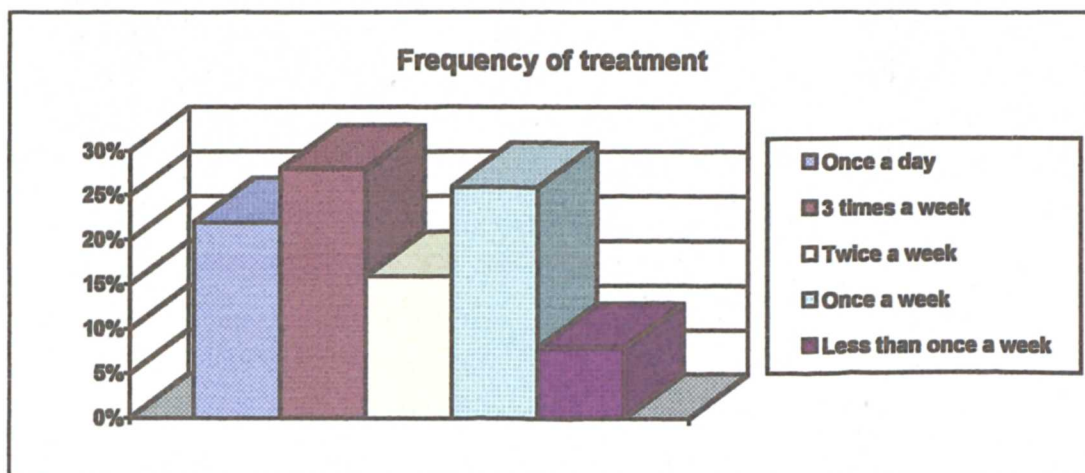


Figure 3 Frequency of treatment

Source: Dale and Gibson, (1986) p.216.

Bosanquet (1992) has reported that the total percentage of working time needed to care for patients with venous ulcers varies. This variation would be expected between areas depending upon the nature of the population served: those with larger proportions of elders requiring more time for this purpose. He reported that in Walsall and Rochester, the nurses spent between 30-50% of their time treating patients with ulcers, whereas in Norwich the figure was between 10-20%. "The mean frequency of ulcer dressing was 8.5 times per month and the mean length of time taken was 15.4 minutes"(p.44). In Riverside District, 75% of the nurses were spending at least a quarter of their time with these patients. This is of considerable interest to health care planners because the main cost of care is the time of the nursing staff. The average cost of a home visit in Riverside was estimated as £25.00 (Moffatt and Stubbings, 1990, p.6) but there is considerable variation due to the time a home visit may require. An analysis of the cost of District Nurses caring for patients in Bedfordshire, for example, found that a home visit could be as expensive as £52.00. Some patients had been visited daily for ten years and during a three month audit period the nurses had made 5,477 visits to patients with venous ulcers alone (Tuxhill and Kenmore, 1992, p.26). The annual costs, as estimated

by Bosanquet for the whole of the United Kingdom and based on the figures for Riverside District of London indicate that, depending upon the percentage of nursing time involved, the cost of caring for patients with venous ulcers could be between £228-408 million based upon 1990-91 prices. Each patient would require a expenditure of approximately £1067.00 per year and of this figure £670.00 would be the cost of nursing care (Bosanquet, 1992, p.44). Table 4 shows the estimates of treatment costs as they vary with the percentage of District Nursing time that the patients require.

Percentage of District Nursing time	Cost of community nursing time	Bandages /dressings	Outpatient /inpatient costs	GP prescribing/ consultation	Total
15	108	50	50	20	228
25	180	50	50	20	300
33	240	50	50	20	360
40	288	50	50	20	408

Table 4 Treatment costs of venous ulcers in 1990-91 (£ million)

Source: Bosanquet N (1992) p. 45.

As the average age of the population increases there are serious concerns over the potential costs in the future. In view of the present level of cost, new approaches have been tried to bring about savings as well as increasingly positive clinical outcomes. Given that the largest costs are in terms of nursing time, this aspect was the obvious focus of attention and innovative approaches are being tried: most noticeably the move towards nurse run community clinics for the care of patients with venous ulcers. The Riverside Community Leg Ulcer Project was perhaps the first in the country to try to reduce the costs of nursing input while at the same time standardising treatment regimens to increase the efficiency of treatment (Moffatt and Oldroyd, 1994). This approach has been copied in a number of areas of the country (Russell, 1992, Awenat, 1992, O'Hare, 1994, for example) in order to improve outcomes. However, despite initial enthusiasm, the longer term outcomes have

not been impressive: this is a remarkably chronic condition often marked by numerous recurrences of ulceration under even the more modern contexts of care. There are other approaches that might usefully be employed and these will be discussed in the final chapter of this thesis.

Venous ulceration: the nature of the problem

In order to understand the pathology the patients in this study suffered from it is necessary to appreciate the anatomical structures and the related physiological mechanisms that act, in the vast majority of the population, to maintain normal pressure within the veins and tissues of the leg. With this background, it is then possible to discuss the opportunities for prevention of the pathology and for its early diagnosis and treatment.

There is considerable variation in the terminology used to describe these wounds: "varicose ulcer", "gravitational ulcer", "stasis ulcer" and "hypostatic ulcer" have been and are still used. Each of these labels is "semantically incorrect" and should be abandoned in favour of "venous ulcer" which accurately describes the nature of the problem (Browse, Burnand and Thomas, 1988, p. 349). It is the venous abnormality that leads to increased pressure in the veins, that is, to venous hypertension, and this in turn leads to increased pressure in the capillaries of the skin of the lower leg. The disordered blood supply to the superficial tissues gives rise to the invariably present signs of "thickened, pigmented and fibrotic skin" that Browse and his colleagues have termed "lipodermatosclerosis" (Ibid.).

An ulcer develops either spontaneously because of the changes that venous hypertension has caused or because of external injury. The wound does not heal as a normal wound would because there is impaired circulatory support for healing and this situation is further aggravated by the local tissue damage caused by the existing and long standing venous hypertension.

In order to manage the trajectory of a patient with a leg ulcer, or better, to prevent its occurrence, the medical and nursing personnel involved in care must have a thorough understanding of the nature of venous hypertension, its causes and treatment. The following section examines five topics: a) the normal anatomy and physiology of the lower leg, b) the primary and secondary prevention opportunities of venous hypertension; c) the normal structures and functions of the skin; d) the process of normal wound healing and e) the specific changes to the structure and function of the skin caused by venous hypertension which complicate wound healing.

a) Normal anatomy and physiology of the lower leg

The pretrajectory phase of any condition is defined as the time "before the illness course begins, the preventive phase" (Corbin and Strauss, 1992, p.17). In this period, the structure and function of the venous system of the leg and of the skin are normal and the life of the individual would be expected to be uninterrupted by the signs and symptoms of venous hypertension.

The effect of hydrostatic pressure

The normal venous pressure in the foot veins is 25 mm. Hg. However, if a person were to stand perfectly still for even a short period of time, the pressure would rise well beyond this physiologically well tolerated level to reach approximately 90 mm. Hg. This increase would be brought about by the effect of hydrostatic pressure and the figure of 90mm.Hg. represents the weight of the column of blood between the foot and the heart in the person of average height. Diagram 1, illustrates the effect of hydrostatic pressure on the venous system.

If this level were to be maintained for even fifteen minutes, as much as 15 -20 percent of the blood volume would be lost from the general circulation (Guyton, 1982, p.154). Normally, a person does not remain motionless for this length of time and even minimal movement, if it causes the contraction of the calf muscles, will pump the venous blood out of the leg and, in expelling it from the lower limb, will reduce the pressure within the veins. In the healthy leg, the normal pressure is maintained by the efficient return of venous blood: a process dependent upon the patency of the veins, the competency of valves within those veins and by the action of the calf muscle pump.

Normal venous drainage of the leg

Blood is able to leave the leg by moving from the arteries into the superficial and deep veins. The deep and superficial veins are connected by the perforator veins, which are also known as the communicating veins because they join the superficial and the deep system of venous drainage. The deep venous system consists of veins and an important feature, the soleal sinusoids, which will be described in greater detail shortly.

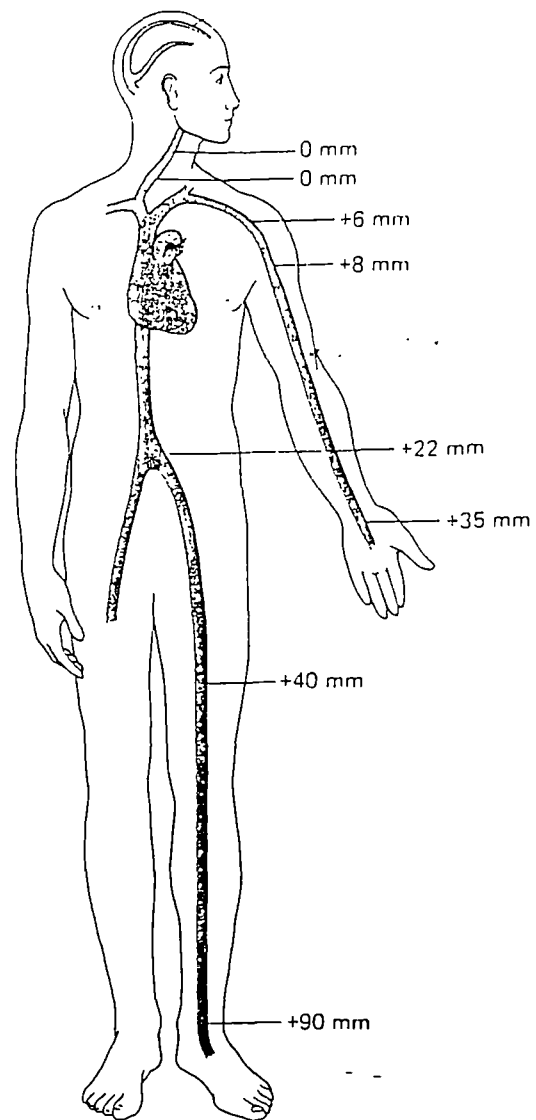


Diagram 1 The effect of hydrostatic pressure on the venous system.

Source: Guyton A C (1982) 3rd edition, p. 154.

The veins of the Leg

Diagram 2 illustrates the principle veins of the leg giving an anterior and posterior view and diagram 3 is a schematic representation of the same vessels. The superficial drainage will first be discussed before considering the deeper system. The metatarsal veins drain from the region of the toe into the dorsal venous arch. The lateral aspect of the arch is drained by the short saphenous vein which runs behind the lateral malleolus and up the back of the calf. At the level of the knee, in the area called the popliteal fossa, it pierces the fascia and drains into the popliteal vein. The medial side of the dorsal arch is drained by the great saphenous vein which passes in front of the medial malleolus and ascends unsupported in the subcutaneous tissue along the medial aspect of the leg. It pierces the fascia at the top of the thigh and joins the femoral vein.

The deep veins of the lower leg accompany arteries. The relationship is expressed most succinctly and clearly by MacKinnon and Morris(1986, p.100) who state that two veins "accompany each of the smaller arteries in the leg and eventually join to form the popliteal vein." They are:a) the posterior tibial veins which accompany the posterior tibial artery and which receive veins from the sural muscles, the venous plexus in the soleus muscles and also connections from the superficial veins and the peroneal veins; b) the anterior tibial veins which are the continuations of the venous companions of the dorsal pedal artery and which unite with the posterior tibial veins to form the popliteal vein; and c) the popliteal vein which becomes the femoral vein. These deeper veins are shown in diagram 4.

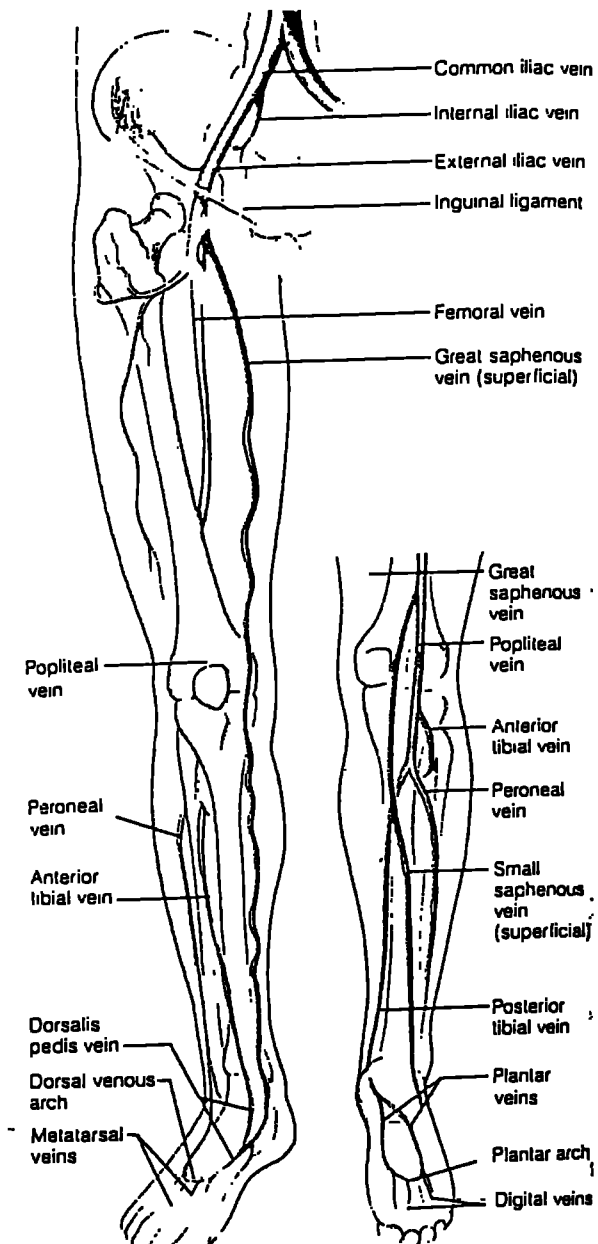


Diagram 2 The veins of the leg, anterior and posterior views

Source: Marieb E N (1992) p.674.

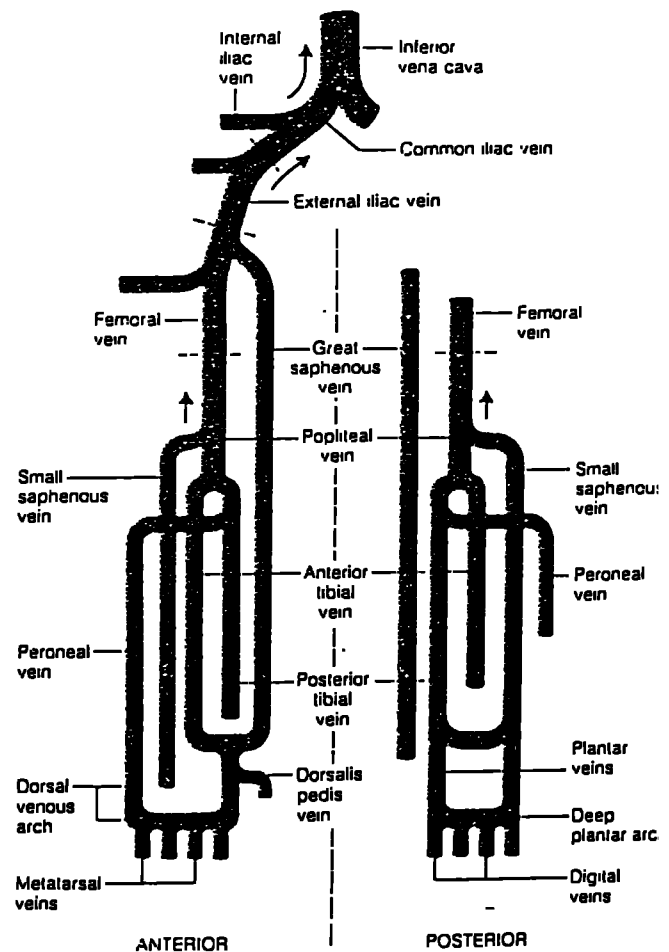


Diagram 3 Schematic representation of the veins of the leg.

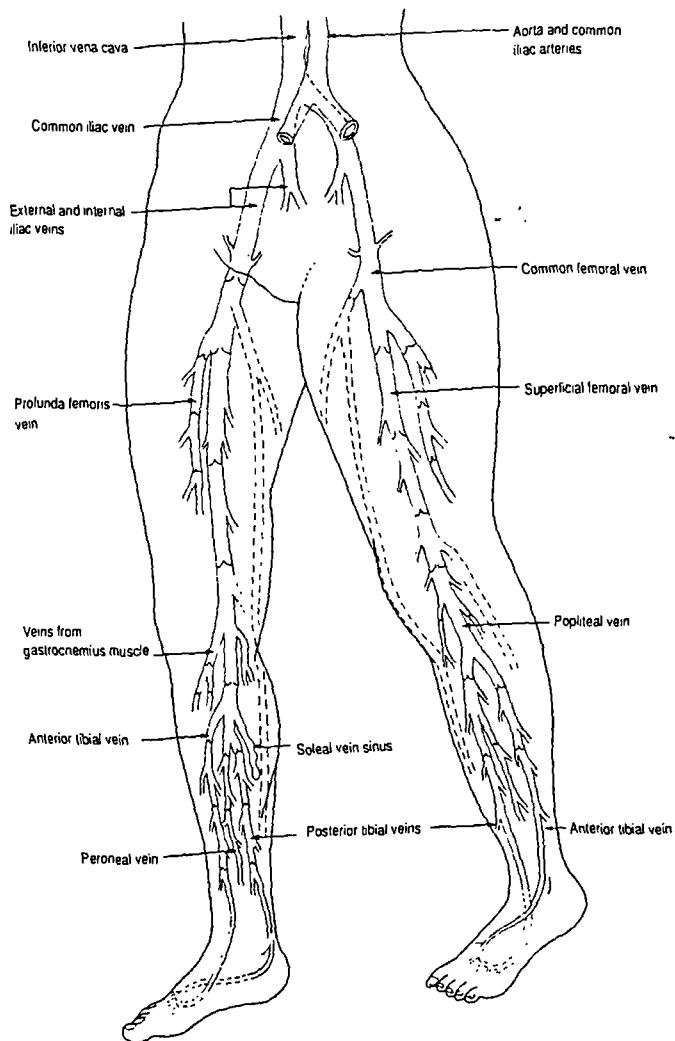


Diagram 4 The deep venous system.

Source: Browse, Burnand and Thomas(1988) p.5.

Perforator(communicating) veins

Between the superficial and the deeper veins are perforator veins. Approximately 50-100 indirect perforating veins enter the muscles before joining the deep veins but these have little significance in the normal leg. However, the direct communicating veins of the lower part of the leg and ankle are of significance because of their anatomical placement. "The lowest lies behind the medial malleolus, the next a hand's breadth above this, and the most proximal another hand's-breadth higher" (Negus, 1991, p.18-19). The valves within the perforator veins permit blood to flow from the superficial into the deep venous system. It is from the deep venous system that most of the blood is pumped against gravity towards the heart. Diagram 5 illustrates the location of the significant perforator veins and shows the one way valves within them.

Soleal sinusoids

The soleal sinusoids are a particularly important feature of the deep venous system of the lower leg. They are chambers which act as reservoirs for blood. As can be seen from the diagram below, the blood which fills them comes from the superficial veins via the perforator veins. In addition they collect blood from the muscles and the deep veins. They have numerous small inlets but blood leaves the chamber by way of a single larger outlet that runs directly into ample sized collecting veins coming from each muscle (Tibbs,1992). They lie deep within the calf muscles and any muscular contraction in the lower leg compresses them and causes the blood within them to be expelled from the calf and moved in the direction of the heart. Diagram 6 illustrates the relationship of the superficial and deeper veins to the soleal sinusoids.

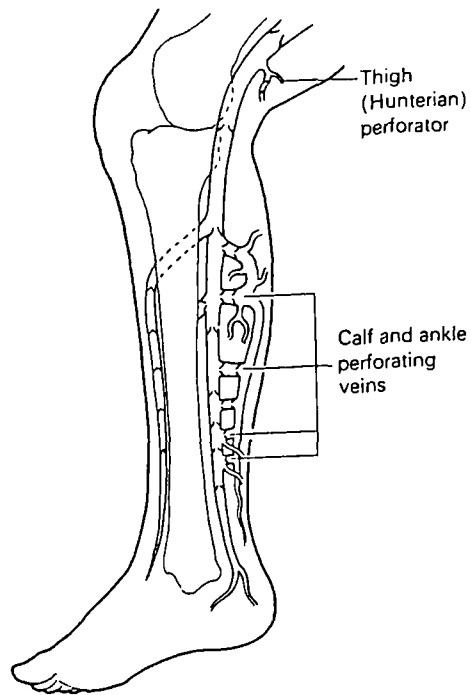


Diagram 5 The location of the significant perforator veins in the lower leg.

Source: Negus D (1991) p. 32.

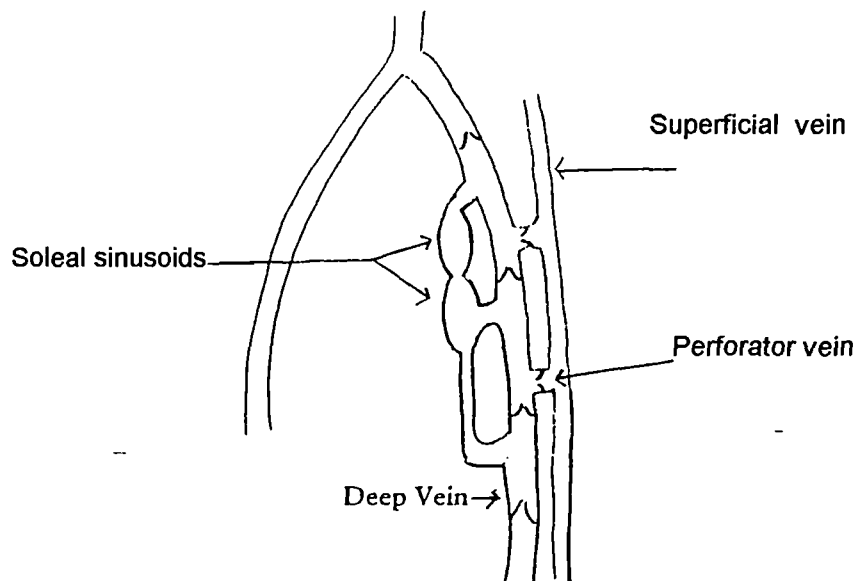


Diagram 6 The relationship of the superficial and deeper veins and the soleal sinusoids. Patterned after: Negus D (1991) p. 28.

The calf pump

In order to understand the calf pump as a mechanism for lowering venous pressure in the lower leg it is important to appreciate the relationship of the veins to the muscles of the calf area. Numerous veins and the soleal sinusoids lie deep within this muscular chamber. Diagram 7 illustrates this point.

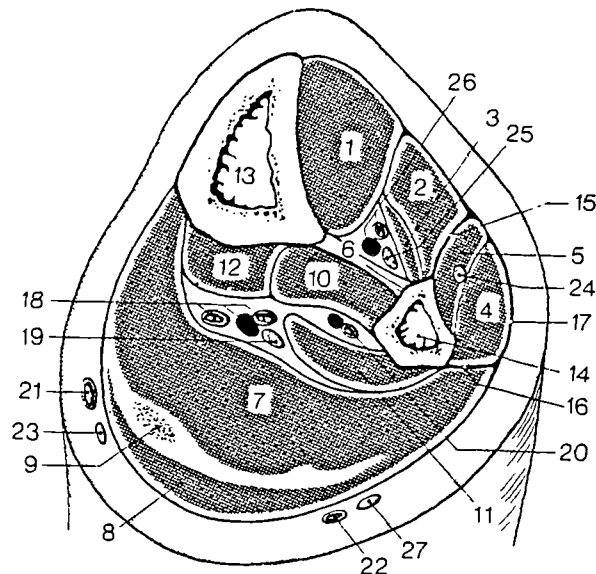


Diagram 7 The principal veins within the calf muscle pump

Key: 18: posterior tibial artery and veins

20: peroneal artery and vein

21: great saphenous vein

22: small saphenous vein

26: anterior tibial artery and vein

Source: Platzer W (1985) p.277.

Action of the calf pump

When the muscles of the calf contract, the veins lying within them are compressed and blood is forced centripetally against gravity. The pressure within the deep veins will, as a consequence, be lowered and on relaxation of the muscles, blood will be drawn from the superficial vessels from the area of higher to lower pressure. The result of this contraction and relaxation is the decrease of venous pressure in the feet to approximately 25 mm Hg.(Guyton,1982). This effect can be achieved by any movement that causes contraction and relaxation of the calf muscles. Diagram 8 illustrates the action of the calf pump on the pressures within the veins of the lower leg.

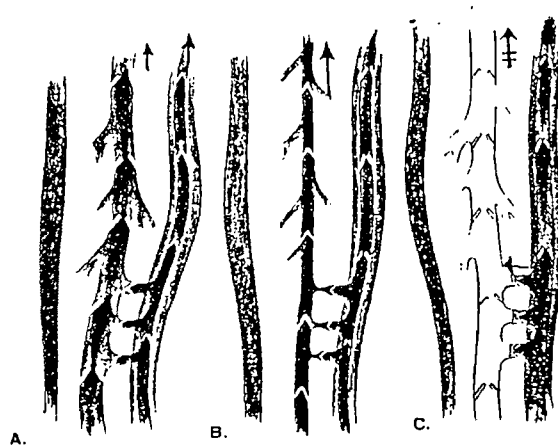


Diagram 8. The action of the calf muscle pump
Source: Jakobsen B H (1987)p. 2162.

A: The muscles are relaxed and pressures within the venous system are equal in the superficial and deeper systems.

B: Muscular contraction causes compression of the veins within the calf pump area. These veins are emptied by this pressure. Due to the one way valves, the blood is forced upward and out of the limb.

C: Muscular relaxation occurs and the level of pressure in the deep veins is lower than in the superficial system. Blood flows through the perforator veins into the deep veins. The pressure within the system is equal again until muscular contraction occurs.

Summary of the maintenance of normal venous pressure in the lower leg

In summary, it can be said that the normal, physiologically well tolerated level of pressure of 25 mm. Hg. within the veins of the lower leg is achieved and maintained by the action of the calf muscle pump acting on the normal venous drainage system of the leg. The contraction of the calf muscles exerts a milking action on the blood within the veins and the soleal sinusoids and forces it out of the lower leg and moves it towards the heart. The role of the perforator veins is to conduct venous blood unidirectionally away from the superficial vessels and into the deep venous system. The health of the tissues of the lower limb depends upon the structures and on their efficient functioning.

b) The primary and secondary prevention of venous hypertension

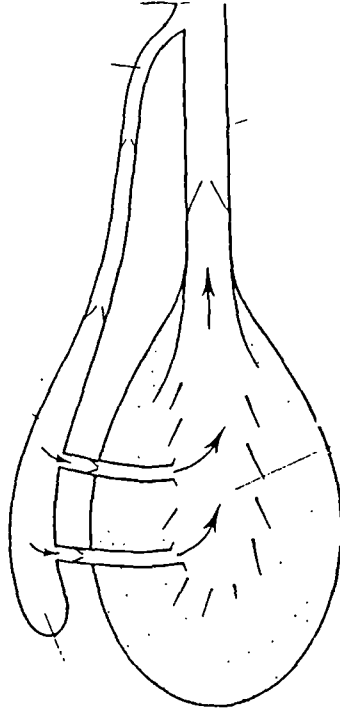
Primary prevention involves preventing a disease from occurring and secondary prevention involves screening for the presence of disease before symptoms become obvious (Stanhope, 1988, p. 59). "By definition a venous ulcer cannot exist in the presence of normal calf pump function" (Browse, Burnand and Thomas, 1988, p.353). Therefore, it is conditions that threaten normal calf pump function that one must prevent in the pretrajectory or primary prevention phase and conditions that have caused venous hypertension to occur that one must detect in order to initiate strategies in secondary prevention. At present there is only one method of primary prevention possible and that involves preventing venous thrombosis. There are many opportunities for secondary prevention however, and most of these are missed because of lack of knowledge on the part of the health professionals concerned.

Deep vein thrombosis

It is estimated that between 33 and 55 percent of patients with a venous ulcer have evidence of deep vein thrombosis in the lower leg (Sethia and Darke, 1984, p.754 and Negus and Friedgood, 1983, p.623). The presence of a thrombus within the calf pump area would have two immediate effects: it would decrease the space available to hold the venous blood delivered to the area and it would impede the pumping action of the muscles. If the outflow of blood from the calf pump area were occluded by a thrombus, the pressure within the pump would increase and in turn could cause dilatation of the pump chamber. The raised pressure, unable to resolve itself through the movement of blood through the deep venous system, would be transmitted outwards, superficially, through the perforator veins. This reflux action would damage or eventually destroy the valves. Diagram 9 illustrates the normal pattern of blood flow and diagram 10 shows the effects when obstruction is present. Each subsequent contraction of the calf pump would then produce raised pressure in the superficial veins, increased overall venous pressure in the leg, oedema, congestion, poor tissue perfusion and eventually perhaps ulceration. Once this damage has occurred it is permanent. No surgical techniques currently exist to repair damaged valves successfully or to deal with the deep venous disorder.

Saphenous vein

Deep outflow tract



The deep pump compartment

Diagram 9.

Normal pattern of blood flow in the lower leg.

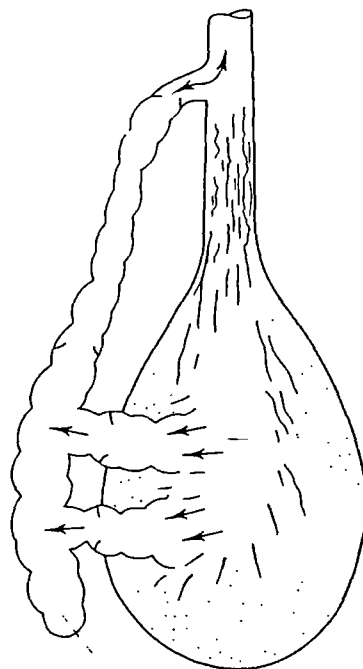


Diagram 10. Effects of obstruction.

Source: Browse N L, Burnand K G, Thomas M L (1988) pages 59 and 64 respectively.

Primary prevention of deep vein thrombosis

Surgical patients are at risk of developing deep vein thrombosis and the operations most commonly associated with the condition are: laparotomy, thoracotomy and pelvic surgery. Negus, Freidgood, Cox, Peel and Wells(1980) carried out a double blind trial on ninety five post operative patients and each received either normal saline or heparin by infusion. Eleven (twenty two percent) of the saline group but only 2 (4.4 percent) of the heparin group developed deep vein thrombosis. This result was statistically significant at the $p < 0.01$ level. It would seem that the only realistic method of primary prevention for deep vein thrombosis is one in the hands of the surgeons. Nursing activity directed towards minimising venous congestion and the threat of deep vein thrombosis in the post operative period would include early ambulation where appropriate or exercises for the bed bound but the key factor would seem to be one in medical hands.

Secondary prevention of venous hypertension

i) Musculoskeletal disorder of the ankle joint

The calf pumping mechanism of the leg may fail due to joint fixation arising from disease or injury. Rheumatoid arthritis occurs with increasing frequency with age and usually affects the small peripheral joints in a symmetrical fashion; the noninflammatory degenerative changes of osteoarthritis do not normally affect the ankle and feet unless there has been a history of trauma and this of course could give an asymmetrical presentation depending upon the initial injury (Matteson, 1988, chapter 7). Should the pain of inflammation from disease or injury cause the person to limit walking and to adopt a style of walking that prevents normal flexion and extension of the ankle, eventually joint mobility could be compromised. The ensuing failure of the pump would then be secondary to the pathology or injury in the ankle joint. In the Lothian and Forth Valley Leg Ulcer Survey, Ruckley and his colleagues(1982, p.615) noted that of 827 legs with chronic ulceration, 32 percent had a severe limitation of the ankle joint movement. Normal calf pump function requires the movement of the ankle joint. If joint mobility is

compromised it may in turn prevent the venous pressure from being kept within physiologically tolerable limits and damage might ensue.

Gaylarde and his colleagues(1990, p.142-143) suggest an alternative mechanism to explain the decreased efficiency of the calf pump secondary to arthropathy. Noting that it is accepted that venous insufficiency is associated with periostitis and muscle changes they propose:

" that the association between venous leg ulcers and arthropathy in the lower leg is the result of two reciprocal processes: impairment of venous return by arthropathy and the induction of an inflammatory arthropathy when venous return is compromised"(p. 143).

Primary/secondary prevention of venous hypertension secondary to musculoskeletal disorder

In the case of clients who have arthritis or a history of injury to the lower leg, the nurse might assess the mobility of the ankle joints and provide health education that emphasised the importance of the pumping action of this joint. Attention to this aspect of self care might reasonably be expected to reduce the movement of clients into the trajectory phase. However, if injury produced immobility of the ankle joint or damage to the perforator veins sufficient to compromise function, then the client would already be affected by venous hypertension. *A number of clients present with leg ulcers and have a history of trauma to the lower legs.* In such cases secondary prevention would provide early warning of the changes due to venous hypertension and prevention of ulceration might be possible at this stage through compression hosiery, elevation, and exercise, for example.

ii) Venous Abnormalities of the Lower Leg

Saphenous vein incompetence, that is, the inability of the saphenous vein to promote the movement of venous blood away from the lower limb because the functional ability of the valves within them has been compromised, is commonly seen in the condition known as "varicose veins". Varicose veins occur in approximately half of the population but only a small percentage of these people have varicosities of medical significance, that is, serious enough

in nature to require medical or surgical intervention. In the Basle Study (Widmer, Kamber and Leu, 1978, p. 68-70), which was the largest study of peripheral vascular disorder undertaken in a population of workers, it was found that of the 4529 workers examined by the medical researchers, 9% of the men and 9.1% of the women had a "relevant varicosity", that is, medically significant varicosities and 3.9% of the men and 3.0% of the women had a "pathological varicosity", that is, a varicosity occurring with evidence of skin and/or vein changes that indicated venous hypertension: dilated superficial veins, evidence of leakage from capillaries and staining of the skin, or areas of depigmentation, or evidence of existing or healed ulcers. Open ulcers ("ulcus cruris" in the study) occurred in 1 percent of the workforce. The researchers noted an almost linear increase in the occurrence of pathological varicosity with age.

Varicose veins can be a progressive problem for the individual. When a vein starts to dilate the cusps of the valves separate and thereby become incompetent and as a result, increasing pressure is placed on the subsequent sections of the vein. Possible complications of varicose veins range from eczema, pigmentation, lipodermatosclerosis, deep vein thrombosis and ulceration (Browse, Burnand and Thomas, 1988, p. 165). Varicose veins can occur as a primary condition, that is, as the only pathology, or they can be a secondary problem occurring as a sequel to disorders such as deep vein thrombosis. If the patients with primary varicose veins of medical significance could be diagnosed and treated, it is reasonable to assume that the numbers of patients presenting with complications including venous ulcers, would decrease. Sethia and Darke (1984, p. 754) examined 417 patients with significant chronic venous disorders of the lower limb and found that 299 had primary varicose veins uncomplicated by additional signs of pathology. A further 118 patients had primary varicose veins complicated by symptoms such as pain, swelling and skin changes. Of these 118 patients, 60 had actual ulcers at the time of referral and the remainder had a history of ulceration. In this subgroup 10 percent had incompetent saphenous veins and perforator veins as the only pathology. Therefore it can be said that the accurate diagnosis of varicose veins of medical significance is of considerable importance because

the treatment of primary varicose veins with or without perforator incompetence could be viewed as a preventive/curative measure of the venous ulceration trajectory.

Secondary prevention of varicose veins

It has been noted that a predisposition to varicose veins is inherited (Hauge and Gunderson, 1969, p.346) but as the condition occurs so often in the general population their figures, though demonstrating a higher than expected prevalence, do not indicate a pattern for such transmission. The more recent work of Haardt(1987) indicates that perhaps individuals inherit an enzyme defect that influences the muscle of the vein walls. In any event, prevention in terms of inheritance is at this point not possible as no specific gene location has been identified. Other factors that seem to be associated with varicose veins include: age, female sex, parity, race and occupation. Certainly the research indicates that the older a person, the more likely he or she is to have varicose veins, but this factor, like one's sex, obstetric history, race or occupation are not amenable to manipulation. Being overweight is another factor that has been associated with varicose veins in women (Brand et al., 1988, p. 97-98) however, in the Basle Study (Widmer, Kach, Madar and Kamber, 1978, p. 64) the influence of this factor is questioned.

Whereas primary prevention of varicose veins is not realistic at this time, the appropriate management of patients with the condition would be expected to prevent movement along the trajectory towards ulceration and in some cases would eliminate the actual cause of the trajectory.

Summary

The concept of an illness trajectory incorporates the possibility of shaping the illness experience and how the shaping is accomplished will depend to a large extent upon the trajectory projections of the individuals involved. The general practitioner could shape a trajectory by referring or deciding not to refer, patients with varicose veins to a vascular surgeon. The surgeon could do so by managing the surgical trajectory in the light of his professional

experience and his knowledge of research findings. The nurse might shape by assisting with early mobilisation, encouraging the use of antiembolism stockings and by health teaching aimed at increasing the patient's awareness and appreciation of the surgeon's trajectory scheme. The patient has a central role in shaping the trajectory because he or she will decide when to seek medical help and whether to comply or reject any treatment offered.

The venous hypertension trajectory begins when the normal structure and function of the venous system of the leg is compromised. The key factors in the development of venous hypertension appear to be the presence of varicose veins or the complication of deep vein thrombosis following surgery. In the former case nothing can be done to prevent the condition at this time. In the latter, the medical management of surgical patients in the post operative period would seem to be the greatest single factor in preventing deep vein thrombosis. The nurse's role in prevention is only within primary prevention if she works on a surgical ward and administers the anticoagulant agents. Usually her work begins in the trajectory phase once the condition has become established. She could play an increasingly important part in secondary prevention if such screening were seen to be of value. Without a professional interest in secondary prevention, the patient will continue to be the first one to notice the early signs and symptoms of venous hypertension and will continue, typically, to present himself at the surgery only when a wound fails to heal as anticipated. Only with a thorough understanding of venous hypertension will the health professional connect precursor signs and symptoms with the actual trajectory in time to prevent or delay the onset of a venous ulcer.

c) The normal structure and function of the skin

The skin has two main functions: protection and temperature regulation. In the pretrajectory phase the skin is normal in anatomical structure and is intact. Likewise, the physiological processes, in the healthy state, occur without complication or the need to adjust to pathological conditions occurring locally or systemically. Unless otherwise stated, all the material in this section is based on Gray's Anatomy, (1989) 37th edition .

The normal gross structure of the skin is shown in the diagram below.

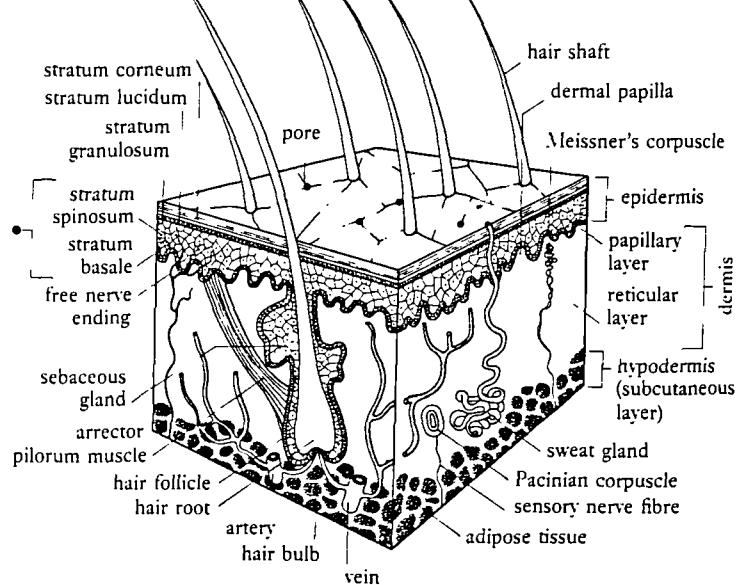


Diagram 11 The normal anatomy of the skin

Source: Brooker (1986) p.490

The skin has two main divisions: the epidermis or outer layer and the dermis. *The epidermis consists of five layers and contains, basically, four types of cell.* The five layers, listed from the deepest to the surface layer are:

the stratum corneum,
the stratum lucidum,
the stratum granulosum,
stratum spinosum, and
stratum basale.

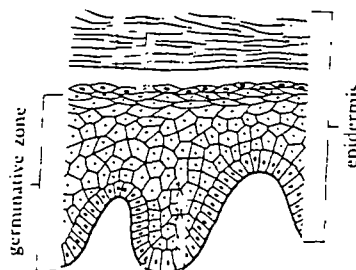


Diagram 12 Epidermal layers

Source: Brooker (1986) p. 491.

Of these layers the stratum basale, spinosum and granulosum are metabolically active and are collectively known as the germinative zone or stratum Malphigii. The stratum lucidum, (present normally only in the thick skin of the soles and the palms and included here for completeness) and the stratum corneum are together known as the cornified zone.

The epidermis consists primarily of stratified squamous epithelium, that is, a multilayered tissue which is constantly undergoing the processes of cell formation, maturation and loss. The cells formed in the basal layers are generally cuboid or columnar in shape. As they move upwards within the epidermis these cells undergo transformation: their shape becomes flattened and their structure is altered. Eventually, at the surface of the skin, they will be shed.

The keratinocytes

Of the four major types of cells present in the epidermis, the keratinocytes are the most numerous. Formed by mitosis of the stem cells in the stratum basale they gradually move upwards towards the surface of the skin. As they move from the stratum basale, the cell surfaces become very folded and tightly interlocked with adjacent cells. They appear spiny and are called "prickle cells" in the stratum spinosum. As they move upward from this layer they begin to flatten and start to synthesise a dense basophilic protein called keratohyalin which mingles with the keratin filaments giving the next layer, the stratum granulosum, its granular appearance and name. The cells at this phase, synthesise and secrete a glycolipid that coats the cell surfaces and forms a thick adhesive, water resistant lipidic cement between the flattened cells. They then lose their nuclei and as dead cells form the stratum corneum.

The melanocytes

The melanocytes are pigmented cells. Their number and position is determined by genetic, hormonal and environmental factors. The hormonal influences include the melanocyte stimulating hormone from the adenohypophysis as well as oestrogens and progesterone. The main

environmental factor affecting the location and number of melanocytes is ultraviolet light which causes the darkening of melanin on short exposure. This process is photo-oxidative in nature and reverses if the exposure is discontinued. On longer exposure the melanocytes are stimulated to multiply providing greater protection for the person exposed to ultraviolet radiation. Generally speaking they are found in the base of the epidermis.

Nonpigmented granular dendrocytes

The Granstein cells and the Langerhan's cells are involved with the protection of the body from infection. The Granstein cells interact with suppressor T cells and the Langerhan's cells with helper T cells thus assisting in the skin's immune response. The Langerhan's cells are derived from bone marrow and are constantly renewed. They have filaments that spread between the surrounding cells. In addition to their function in the immune response, they are sensitive to ultraviolet light.

The dermis

The deeper section of the skin lying underneath the epidermis, the dermis consists of a mixture of irregular and moderately dense soft connective tissue containing collagenous and elastic fibres, blood vessels, nerves, glands and hair follicles. Mechanically this layer provides considerable strength and elasticity. It is divided into two zones: the papillary and the reticular.

The papillary layer

This layer is the upper region of the dermis and makes up approximately one fifth of the thickness of the total layer. The loose connective tissue which contains fine elastic fibres is specialised to provide mechanical anchorage, metabolic support and cell maintenance. The upper surface is marked with papillae (the structures that give rise to fingerprints). Lying underneath each epidermal ridge are two longitudinal rows of papillae. Each papillae contains narrow, densely woven bundles of type 1 and 111 collagen fibres. (Type 1 is the predominate form in healthy skin; type 111 is less well represented and occurs with increased frequency in the early stages of tissue healing) Some

papillae contain loops of capillaries, others may contain Meissner's corpuscles which are sensitive to touch.

Reticular layer

This lower layer of the dermis contains bundles of collagen fibres, mostly, type 1. The collagen fibre bundles are thicker than those in the papillary layer but they interlace with them and with each other. Spaces between fibres are occupied with small amounts of adipose tissue, hair follicles, nerves, oil glands, numerous lymphatic vessels and the ducts of sweat glands. The reticular layer is attached to the underlying structures of bone and muscle by the subcutaneous layer. The subcutaneous layer contains Pacinian or lamellated corpuscles which are nerve endings sensitive to pressure.

Innervation of the skin

The skin has a rich nerve supply that is predominately concerned with the two major functional roles of the skin as a sensory organ and as a thermoregulator. These functions are mediated by the regional sensory and efferent sympathetic fibres of the cranio-spinal nerves respectively.

Cutaneous sense

Mechanical, thermal and other stimuli are sensed by a variety of specialized neurons. Efferent autonomic fibres of the non-myelinated, noradrenergic and cholinergic type innervate the arterioles, arrector pili muscles(the muscles that move the hair follicle) and the myoepitheliocytes of the sudorific(sweat) and apocrine(oil) glands as well as the nonstriated muscle of the dermis and adjacent connective tissue. Thus, the responses required by the body for thermoregulation are triggered in the skin and vasodilatation or constriction of blood vessels, of sweat production or shivering are initiated as appropriate.

Vascularisation of the skin

The metabolic demands of the skin are not generally great because the majority of it is dermal matrix which contains comparatively few cells. Relatively few capillaries are present in the deeper very fibrous layers of the dermis.

Blood enters the skin through small arteries that penetrate into the reticular layer. Here they form a sheet like plexus called the "rete(net) cutaneum" at the interface of the dermis and the superficial fascia. From this plexus arterioles supply the adipose tissue, sweat glands and hair follicles. A second plexus is formed at the junction of the reticular layer and papillary layer of the dermis and this is called the "rete subpapillare"(the network beneath the papillae). These capillaries loop into the dermal papillae before passing back into a venous plexus just beneath the arteriolar papillary plexus. This layer in turn drains into a plexus in the reticular layer and again into another close to the deep arteriolar reticular plexus.

In the deeper layers of the dermis, arteriovenous anastomoses are common particularly in areas of the body subject to cooling such as the hands, feet and ears. Glomera, which are small units of arteriovenous anastomoses, are present in large numbers in these areas. Each glomus has one or more afferent arteries stemming from branches of cutaneous arteries approaching the surface. Under autonomic vasomotor control these vessels, when relaxed, divert blood away from the superficial plexus and therefore reduce heat loss while ensuring some cutaneous circulation and preventing anoxia.

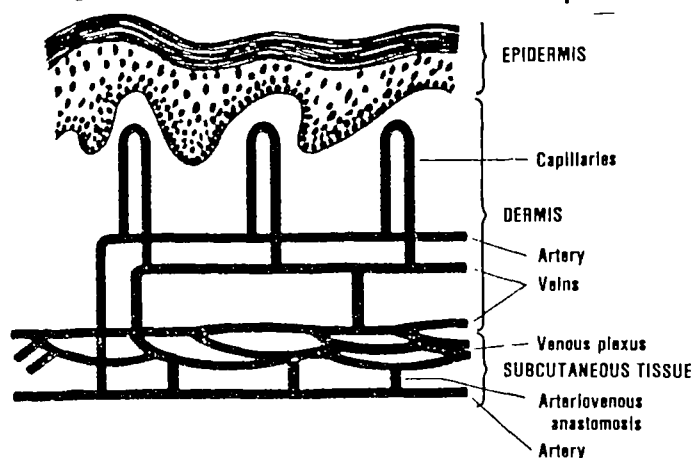


Diagram13. Vascularisation of the skin
Source: Guyton (1982) p.189.

Lymphatic drainage

Lymphatic vessels occur in tissues throughout the body with the exceptions of the central nervous system, the bone marrow, the splenic pulp and avascular tissue. Lymphatic tissue is essentially a specialized form of reticular connective tissue and has two main functions: drainage and defense.

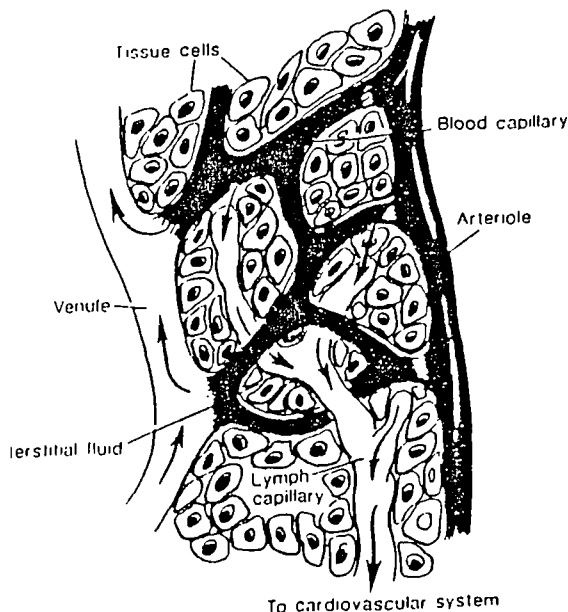


Diagram 14 Relationship of lymph capillaries to tissue cells and blood capillaries

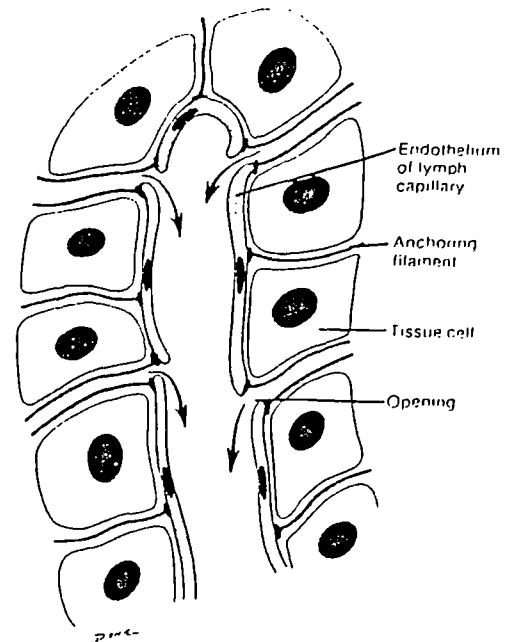


Diagram 15 Details of a lymph capillary

Source: Tortora and Anagnostakos(1990) p.655-656.

The lymph vessels drain the tissue spaces (interstitial spaces) of protein containing fluid and return it to the circulatory system. Under normal conditions small quantities of protein can escape from the capillaries but cannot be reabsorbed directly. The prolonged presence of these substances in the tissues would be highly irritating and cause inflammation. The skin is well served and protected by numerous lymphatic capillaries in the reticular layer of the dermis which drain into plexuses within that layer and which, in turn drain into wider vessels within the superficial fascia. The protein rich fluid enters the lymphatic vessels through minute pores that act much like the one way valves

in veins, ensuring that outward movement of fluid is prevented. Under conditions of increased fluid in the tissues (oedema) the lymphatic vessels are structurally organised to respond with greater efficiency. They are anchored to the local tissues by means of filaments and distension in the tissues surrounding them causes the filaments to stretch and this reaction opens the pores more widely to allow increased drainage.

The defence function of the lymph is to recognise and respond to foreign cells, substances, cancer cells and microbes. These are detected and destroyed through the direct action of the T lymphocytes or the indirect action of the B lymphocytes which differentiate into plasma cells and secrete antibodies (Tortora and Anagnostakos, 1990, p. 655).

Age related changes in the skin

From about the age of thirty five the skin starts to reflect age related changes such as epidermal and dermal atrophy. The elastic fibres lose some of their elasticity and this in turn produces wrinkles. The fibroblasts decrease in number and this reduces both collagen and elastic fibre production. The macrophages become less efficient as phagocytes and resistance to infection is thus decreased. The blood vessels are subject to the atrophy and sclerosis and decrease in number. The layer of subcutaneous fat decreases, the sebaceous glands atrophy causing the skin to dry and become less able to protect itself from infection and trauma. The melanocytes function less well but some increase in size producing "liver spots". The net effect of epidermal atrophy and the flattening of the dermal ridges is that there is less resistance in the skin to shear. The net result of age is a thinner organ, that if damaged, takes longer to heal and with more probability of infection.

d)The repair of tissue damage: wound healing

Introduction

An understanding of the process of wound healing and an awareness of factors that can enhance or impede the process in the special circumstances of venous ulceration are essential for the nurse because they give direction to her professional practice. In this section the process of wound healing is discussed. Following this section, the special problems posed by venous hypertension in the superficial tissues are examined.

When an ulcer develops, usually triggered by an external injury, the two main functional roles of the skin as a sensory organ and as a thermoregulator are disrupted. A wound, by definition involves "...at least a disruption of the tissue layer representing the environmental barrier..."(Cuono, 1985, p.2). How quickly and how successfully a wound heals depends upon its type and location as well as the capacity of the person to provide the materials and energy required for repair.

Wound classification

Wounds involving the skin are routinely divided into two categories depending on the cause: a)intentional, of which surgical incision or excision would be typical examples, and b) accidental, which would include traumatic lacerations, stab wounds, burns, and abrasions. They are also, by convention, divided into two categories depending upon the depth of tissue damaged. A partial thickness wound involves damage to the epidermal and dermal layers, while a full thickness one extends beyond these layers into the subcutaneous tissues(Bryant, 1992, p. 35). In the case of the patient with a leg ulcer the cause is often traumatic in nature and the depth can be either partial or full thickness.

The healing of wounds to the skin is also divided into two categories depending on the degree of apposition of the tissues involved. A wound healing by primary intention is one in which the edges are held closely together by some form of mechanical aid, for example, a suture. The wound healing by secondary intention, the leg ulcer being an example of this type, is a wound

that heals by granulation. In this situation the defect is gradually repaired by a build up of tissue.

The process of wound healing

The process of wound healing is said to have three or four stages. Bulstrode and his colleagues (1984, p.11) identify three: the inflammatory phase, the proliferative and the differentiation phase. Other writers, for example, Leaper et.al, (1987) describe a four stage model adding a “demolition phase” after the inflammatory. Regardless of the number of stages, the sequence of events is always the same and all attempts to subdivide it are artificial and made for convenience of discussion. The complexity of the process may be seen from the schematic representations as in diagrams 16 and 17. It is important to note that this sequence of events is fixed and that any interventions on the part of the doctor or nurse that alter the chemical balance or cellular composition of the wound will alter the rate of healing.

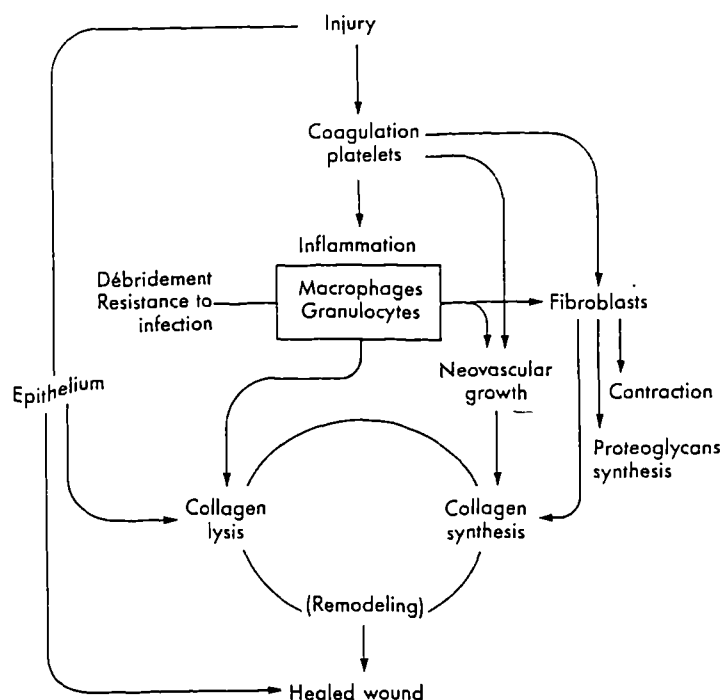


Diagram 16 Schematic representation of the wound healing process
Source: Levenson et al., in Bryant (1992) p. 37.

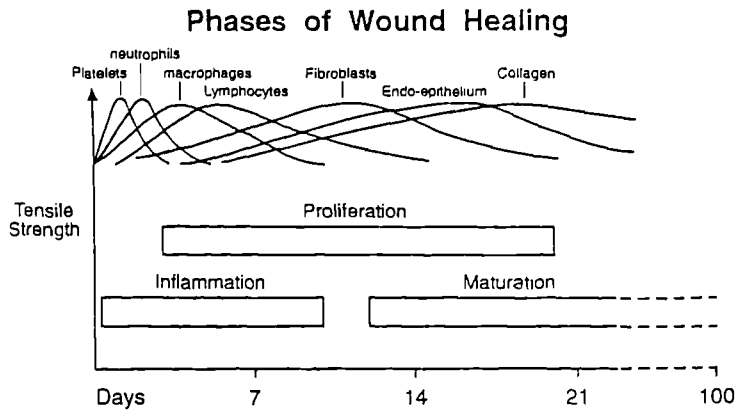


Diagram 17 Relationship of levels of wound constituents to time and phase of healing.

Source: Davis et al. (1992) p.93.

The inflammatory phase

As soon as wounding occurs the intravascular constituents flow into the area and come into contact with collagen. A haemostatic plug is formed. Blood vessels contract after wounding and remain so for a few minutes. There follows a period of vasodilatation that is mediated by the release of vasoactive substances such as histamine from the damaged cells. The ensuing period of increased vascular permeability, lasting approximately 10-20 minutes, is a period of pronounced leakage of serum proteins into the wound. Blood cells escape and a film of fibrin forms over the wound. The cellular composition in and around the wound at this point mirrors that of the circulation. Neutrophils, which are a type of white blood cell, predominate in the early stage following wounding and act as phagocytes, absorbing and digesting foreign material. They have the key role in protecting the wound from infection during the first few days. By the fourth day they are replaced by macrophages. Macrophages come from another type of white blood cell called the monocyte which migrates into the tissues and differentiates into the macrophage. The macrophages, like the neutrophils, are phagocytic and deal with bacteria and particulate matter in the wound. The ingested material is first vacuolised and then by linking with lysosomes, is dealt with by hydrolytic enzymes. Maximum phagocytic activity depends upon the lysosomal membrane being labile and therefore able to

interact with the phagosome (the vacuole in which debris is encapsulated). Substances which increase this lability include: streptolysin, endotoxin, staphylococcal toxin, and increased hydrogen ion concentration (low pH). Substances which interfere with it include: cortisone, aspirin, antihistamines, all of which, it is supposed, act as anti-inflammatory agents in part by stabilising the lysosomal membranes and thereby decreasing macrophage activity. Therefore, patients taking drugs containing aspirin, or steroids, (for the treatment of rheumatoid arthritis for example), antihistamines (those people who suffer from hay fever, or other allergic reactions) might be expected to have lowered phagocytic activity and might as a result experience increased problems with infection in the wound.

The proliferative phase:

a) the role of collagen

By the third day after wounding, fibroblasts appear in the wound. "Fibroblasts are the cells responsible for synthesis of collagen and other connective tissue substances and are therefore critical to the repair process" (Bryant, 1992, p.39). They are "facultative anaerobes", that is, they are able to synthesize in a relatively hypoxic environment which the wound edge represents.

Collagen, the extracellular fibrous framework that gives strength and form to most tissues, is synthesised and extruded into the extracellular connective tissue spaces by the fibroblasts. Seventy percent of the dry weight of skin is collagen (Bulstrode et.al.1984, p. 10).

It is now known that there are at least five genetically distinct types of collagen made up of various combinations of at least seven distinct collagen chains. Five of these chains are known to occur in man. Type 1 collagen is found in skin. Type 111 is found in the foetal dermis and also constitutes approximately one-third of granulation tissue in the early stages of healing. The amount of type 111 collagen diminishes at birth when it is replaced by type 1 and its volume in wounds decreases with maturation. In the wound healing normally, new type 1 collagen will be the predominant type both synthesised and deposited extracellularly. Type 111 is normally synthesised and deposited

in young scars but is replaced by type 1 as the scar matures (Cuono, 1985, p. 13). There is no quantitative change in the total collagen in the skin of older people if the skin has been protected from solar radiation. Smolenski and his colleagues (1987), however, note a change in the ratio of Type 1 to Type 111; the relative amount of Type 111 increasing after the age of sixty-five years. This could affect the healing of ulcers in older people and the subsequent strength of the skin.

Collagen is a glycoprotein and the most abundant protein in the body accounting for approximately 30% of the total protein or 6% of the body weight. Collagen biosynthesis by fibroblasts begins at the DNA level with transcription of data to messenger RNA. The messenger RNA moves into the cytoplasm and attaches itself to ribosomes along the endoplasmic reticulum. Procollagen is first produced. As a precursor of collagen it has an extra peptide sequence at the end of each of the three "a" chains and these will not be cleaved until the procollagen molecule is in place in the extracellular destination.

Collagens are among the very few proteins that contain hydroxyproline and hydroxylysine (together these two make up 20% of the amino acid composition of collagen). These two components are hydroxylised after the amino acids are incorporated into their chain. The hydroxylation occurs due to the action of the enzymes prolyl and lysyl hydroxylase in the presence of the following: oxygen, ferrous ions, and a reducing substance such as ascorbic acid. If any of these is lacking hydroxylation will not occur and an immature and non-functional molecule will be secreted(as happens in scurvy). This situation highlights the importance of the nutritional status of the person with a wound.

After hydroxylation, the procollagen molecule, now in its triple helix form, is transported to the golgi apparatus and then to the cell membrane where it is excreted. Once it is in the extracellular space the procollagen is converted into tropocollagen which is capable of fibril formation. Tropocollagen undergoes fibrillogenesis and this process is followed by the formation of stable crosslinking that give much tensile strength to healing wounds.

Although stable, collagen is never static and it undergoes a constant turnover under the influence of tissue collagenases. The remodeling of

collagen by collagenolysis and the reformation of the collagen fibres brings about a much stronger unit. However, the strength never matches that of undamaged skin (Cuono, 1985, p.16).

The proliferative phase:

b) angiogenesis

New blood vessel growth, that is, angiogenesis, occurs concurrently with collagen synthesis. It is during the proliferation phase that the endothelial buds are noted. This occurs on approximately day 5. The fibroblasts march ahead of the endothelial buds. The buds vacuolate forming a contiguous lumen and further differentiate into arterioles and venules. The growth of new granulation tissue and therefore of connective tissue is critically dependent on this process. Silver(1985, p.18) notes: "It is a matter of common observation that the new vessels grow towards the centre of a wound and thus towards hypoxic regions." Knighton and his colleagues(1981,p.267) postulate that the angioblasts are not responding directly to an oxygen gradient but to a gradient of angiogenic factor produced by hypoxic macrophages (the macrophages do not produce the factor when either anoxic or fully oxygenated). It is during the stage of differentiation that a rationalisation of the copious newly formed blood vessels occurs and many at that period occlude and disappear(Bulstrode et.al.,1985).

During the healing period certain conditions appear to enhance angiogenesis. Cherry and Ryan (1985, p. 64) found when studying chick chorioallantoic membranes that angiogenesis was increased using a hydrocolloid dressing that was impermeable to oxygen. They also studied the differences in angiogenesis in the skin of pigs subjected to 2-4.9 cm. full thickness wounds and covered with either the hydrocolloid or a non-adhesive dressing. They noted that at seven days there was greater vascularity and granulation in the wounds covered by the hydrocolloid. However, at 21 days, this difference from control wounds was less striking. They also looked at oxygen and temperature at the wound sites of two people (p. 67) and they found that the wounds covered with hydrocolloid dressings experienced temperature rises that were maintained over a 24 hour period and lowered oxygen reading over time. These two factors are assumed to speed healing.

The proliferative phase:

c) glycosaminoglycans

Glycosaminoglycans(GAG) is the term that is now used in place of "ground substance". The predominant GAG deposited in the extracellular matrix during the early stages of healing is hyaluronic acid. It acts to prevent the spread of "noxious agents in localized infections"(Tortora and Anagnostakos, 1990, p.664). The level of hyaluronic acid peaks around day five after which it gradually diminishes and is replaced by dermatin sulfate and chondroitin-4-sulfate(both normally present in the extracellular matrix). These two glycosaminoglycans peak about day fifteen and thereafter gradually decline (Cuono,1985, p.14).

The maturation phase: wound contraction

Myofibroblasts, specialised cells having the appearance of fibroblasts but endowed with contractile properties, are present in wounds only for the period for which they are required. Their numbers drop to insignificant levels once epithelialisation occurs. The myofibroblasts infiltrate the wound area by means of microfilaments and it is the subsequent contraction of these filaments that brings about wound contraction (Cuono, 1985, p. 16-17) .

Epithelialisation

The term "contact inhibition" is used to describe the situation in undamaged skin where epithelial cells in contact with each other do not undergo mitosis. After wounding this inhibition is lost. Bullough and Lawrence(1960) have proven the presence of an endogenous inhibitor of mitotic activity in normal dermis, known as chalone(literally, to reduce the speed of). Chalones are glycoproteins of low molecular weight and they are tissue specific. They appear to act by reversibly slowing or prolonging the G 1 or G 2 phases of mitotic division. After wounding the epidermal mitotic rate may reach 15-20 times normal as a result of decreased chalone content in the affected cells(Cuono,1985, p.19). The normal life span for an epidermal cell is 14-21 days, but during repair this is decreased to 4-5 days. At the completion

of the healing process normal epithelial cells meet and contact inhibition halts the process at the surface.

Summary

The process of wound healing is exceedingly complex. Any number of factors have been seen to influence its rate: temperature, nutrition, drugs, for example. In the venous ulcer there is disruption to the anatomy of the skin and the body attempts to heal the wound by the intricate process just described. However, a venous ulcer is not a normal wound but one complicated by the physiological responses in the tissues to venous hypertension. These changes will next be presented.

e. The specific changes in the skin associated with venous hypertension

Despite the advances in recent years there are still unanswered questions in relation to the aetiology of venous ulceration:

“We do not know if a constant high pressure is more harmful or less harmful than short episodes of very high pressure. We do not even know whether the absolute amount, type or persistence of the pressure matter at all! Perhaps it is the tissue reaction to the pressure that matters--sensitive tissues responding to minor changes, insensitive tissues withstanding gross changes. All these questions remain to be answered by properly planned prospective surgical research” (Browse , Burnand and Thomas, 1988, p. 354).

However, it is known that there are skin changes associated with venous hypertension and the research to date has proposed a number of plausible causal mechanisms to account for them. Browse and Burnand (1982) suggest that:

“a high ambulatory venous pressure within the calf-muscle pump is transmitted through the communicating veins to the superficial veins within the skin and the subcutaneous tissues of the calf”(p.244).

The presence of such elevated pressures within the capillaries, they propose, causes maximum enlargement of the capillary bed and distension of the pores in the capillary walls. The increased lumen of the pores allows the escape of macromolecules into the interstitial fluid. Their theory has been named the “fibrin cuff theory” because they state that the most important of these macromolecules is fibrinogen which changes within the tissue to form an insoluble barrier of fibrin. Normally, fibrinogen would be broken down into soluble products and removed from the interstitial tissues through the lymphatic channels but in patients with lipodermatosclerosis and post phlebotic limbs the fibrinolytic activity is significantly depressed. This finding gave rise to a therapy using an anabolic steroid, stanozolol, that stimulates fibrinolytic activity. Diagram 18 illustrates the normal microcirculation and diagram 19, the microcirculation in the condition of venous hypertension. The alterations that occur to the capillary bed are shown in diagram 20.

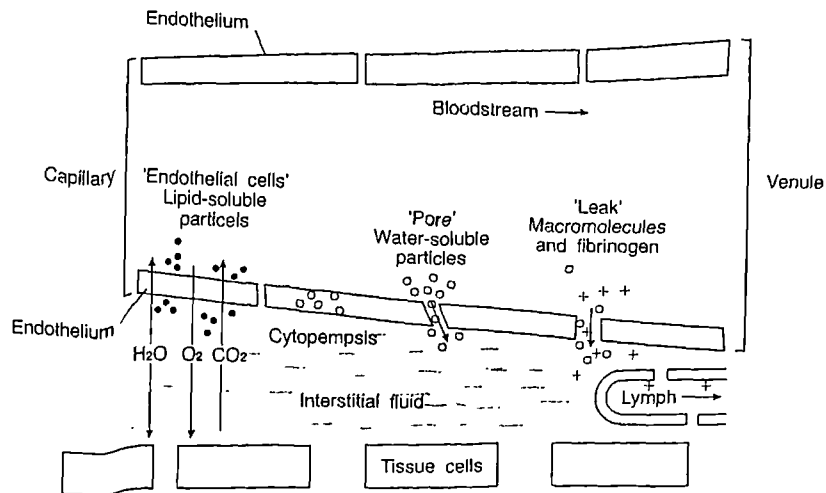


Diagram 18 The normal microcirculation. Under normal conditions fat soluble substances diffuse through the capillary wall and water soluble substances pass through the pores. Excess water and protein are removed by the lymphatics.

Source: Burnand K G (1992) p.9.

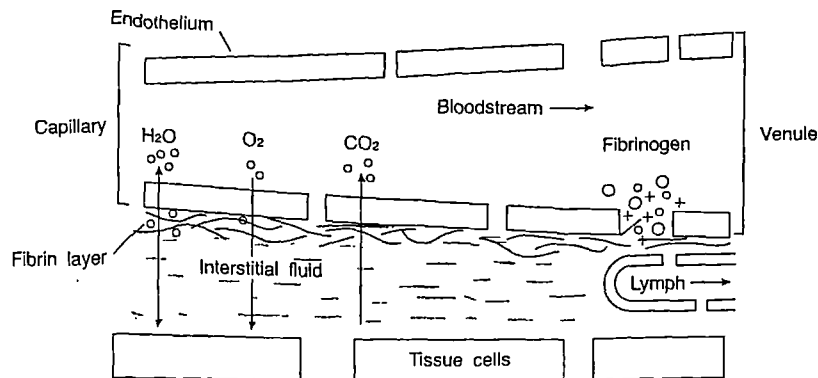
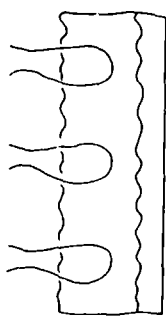
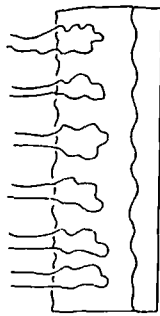


Diagram 19 Microcirculation in conditions of venous hypertension. Fibrin becomes deposited around the capillaries blocking the transport of oxygen and nutrients and causing anoxia. Lipodermatosclerosis, that is the slow replacement of the skin and subcutaneous tissues by scar tissue, occurs in response to anoxia.

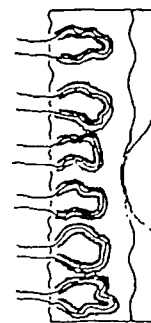
Source: Burnand K G (1992) p.9.



Normal



Venous hypertension
Capillary proliferation



Tissue necrosis

Diagram 20 The normal state of the capillaries and the progression of pathology under conditions of venous hypertension. The increase in the number of capillary loops is followed by fibrinogen leakage and the development of the pericapillary "fibrin cuff"

Source: Browse N L and Burnand K G (1982) p.243.

They produced convincing evidence to support their theory in a report published in 1982 (Burnand, Whimster, Naidoo and Browse, 1982). They examined skin biopsies taken from the ulcer bearing area of forty one legs in twenty-one patients and found pericapillary fibrin deposits in every case. In twenty four of the twenty six legs where there was evidence of lipodermatosclerosis there was an increase in the number of dermal capillaries. A group of fifteen patients, with uncomplicated venous disease, used as controls, did not show pericapillary fibrin and in only two was there evidence of increased dermal capillaries. The difference between the two groups in terms of dermal capillary density was significant at $p < 0.001$ (p. 1071). These findings in themselves do not prove that the presence of a fibrin cuff is the cause of ulceration: they merely associate the two. In an earlier study, (Burnand, Clemenson, Morland, Jarrett and Browse, 1980) the effectiveness of stanozolol in resolving lipodermatosclerosis had been examined. In their double blind cross-over trial they reported rapid clinical improvement in all patients who took the steroid who also had elastic compression applied to their lower legs. The improvement however was in relation to the areas of lipodermatosclerosis and

the amount of pericapillary fibrin and not the rate of healing of the ulcers which was unaffected. The researchers suggested that early action might prevent irreversible damage:

“If fibrin deposition can be reduced at an early stage, before it starts to kill tissue or stimulates irreversible fibrosis, venous ulceration may be prevented. This may be accomplished by surgical restoration of calf pump efficiency, by the use of elastic compression, or by the use of drugs which enhance tissue fibrinolysis” (Burnand , Whimster, Naidoo, Browse, 1982, p. 1072).

Coleridge Smith, Thomas, Scurr and Dormandy entered the debate in 1988. They noted that there were fewer capillary loops visible in a given area of skin after the ten patients in their study had spent thirty minutes with their legs in a dependent position: this finding was unexpected. A dependent limb would be expected to demonstrate the same number or more loops as the pressure of blood increased. It is important to appreciate that the loops are visible because of the presence of red blood cells; the presence of white blood cells cannot be detected by the observer's unassisted eye. Thomas, Nash and Dormandy(1988) reported the results of their study in which they had tested an hypothesis first proposed by Moyses and his team in 1987 that white cells accumulate in dependent and immobile limbs of normal subjects. To do this, Thomas, Nash and Dormandy (1988, p. 1693-1695) examined the ratio of white to red blood cells in samples of blood drawn from the long saphenous veins in patients with known venous hypertension and compared it with that of patients with uncomplicated primary varicose veins and with volunteers without any evidence of venous disease. Blood samples were taken with all subjects supine and again after they had rested in the sitting position with their legs dependent for an hour. After the hour, those patients with “chronic venous insufficiency” had 28% fewer white cells in the samples taken than either of the other two groups and the result was significant at the $p < 0.01$ level. The researchers explained their findings by proposing that some of the capillaries of the affected individuals were occluded by the white cells. They suggested that the lower capillary flow rate which accompanies raised venous pressure is sufficient to cause trapping of white cells. The blockage to normal perfusion

causes tissue hypoxia which is followed by the release of toxic metabolites. It is the metabolites, proposed Coleridge Smith, Thomas, Scurr and Dormandy (1988, p. 1727) that damage the capillaries and make them increasingly permeable to fibrinogen which in turn forms a fibrin cuff. They noted too that the trapping of white cells which was at least partially reversible in their study, might, if more prolonged, produce lasting damage. Summarising their findings, Thomas, Nash and Dormandy (1988, p.1695) stated:

“The repeated accumulation of white cells in capillaries and venules of the foot may contribute to trophic changes of the skin and ultimately to ulceration by several mechanisms.”

They suggested as possible mechanisms: inflammation mediated by hypoxia to white cells, degradation of the endothelial walls of the blood vessels through the release of components usually held within neutrophils, or, increased blood pressure within the vessels that might lead to the release of agents that activate neutrophils. They agree that a pericapillary fibrin cuff forms in areas of increased capillary permeability but they disagree with the cause of the increased permeability. Burnand and his team contend that the high venous pressure is the cause whereas, Coleridge Smith and his group argue that it is the blocking of the capillaries by the white cells that is the initial cause.

Falanga and Eaglestein (1993, p. 1006) offer an alternative “trap” theory. They proposed:

“that fibrin and other macromolecules that leak into the dermis ‘trap’ growth factors and other stimulatory or homeostatic substances, and render them unavailable for the maintenance of tissue integrity and the repair process.”

This situation is illustrated in diagram 21 in which the microenvironment of a normal wound is compared with that of a venous ulcer.

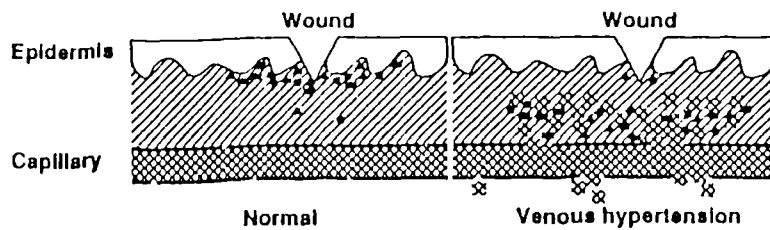


Diagram 21 The microenvironment of a normal wound and a venous ulcer. Note the “trapping” of growth factors below the wound.

Source: Falanga V and Eaglestein W H (1993) p. 1007.

They built their hypothesis on the previous studies and accepted that fibrin cuffs form in response to either venous hypertension or to endothelial injury. However, because they found that venous ulcers can heal in the presence of fibrin cuffing (Falanga, Kirsner, Katz, Gould, Eaglestein and McFalls, 1992, p. 409), they are unwilling to accept the simple barrier explanation of Burnand and his colleagues. They found that venous ulcers characteristically contained both fibrinogen, growth factors and alpha macroglobulin which is a binding agent for growth factors. However, they note that the growth factors in venous ulcers seem to be inactive (Higley, Ksander, Gerhart, Kirsner and Falanga, 1992, p. 33-34). Previously, Bucalo, Eaglestein and Falanga, (1989, p. 539) had examined the wound fluid in venous ulcers and found it to be unsupportive, even inhibiting of fibroblasts and endothelial cells, both of which are required for healing. As the environment for wound healing is definitely disordered in conditions associated with venous hypertension, Falanga and Eaglestein (1993, p. 1007) concluded that “The mechanism would re-emphasize the need for more effective compression therapy to decrease venous hypertension.” Their work might lead to the development of treatments aimed at activating the trapped growth factors from the dysfunctional wound site.

Summary

The fibrin cuff theory has enjoyed and still has a considerable following. However, the work of Balsev and her colleagues (1992, p. 583) provides evidence that it is not simply venous hypertension that gives rise to fibrin cuff formation. They surgically removed chronic leg ulcers from thirty three patients.

Nineteen specimens were venous ulcers and fourteen were ischaemic in origin: all had pericapillary fibrin deposition. It is of interest that: "Fibrosis (lipodermatosclerosis) was found in all the venous hypertension ulcers and in all ischaemic ulcers" (p. 584).

The venous hypertension specimens showed greater fibrotic changes but "No correlation could be established between the grade of pericapillary fibrin deposition and the grade of lipodermatosclerosis" (p. 584). They concluded that:

"the observed deposition of fibrin is a secondary physiological phenomenon which occurs in an ulcerated skin area and that the fibrin observed in non-ulcerated areas is a result of 'spill over' from the ulcers. Consequently, the hypothesis that fibrin deposition plays a major causal role in the formation of a chronic venous hypertension ulcer cannot be supported" (p. 585).

The white cell trapping theory is attractive but as Shami, Sheilds, Scurr and Coleridge Smith (1992, p.783) note:

"The first part of the 'white cell hypothesis' suggesting tissue hypoxia as a result of capillary plugging cannot be supported, as there is no proof that there is tissue hypoxia in LDS (lipodermatosclerotic) skin."

In fact, the contrary is true. Peters and his colleagues (1991, p.177-178) studied the subcutaneous blood flow during walking and passive dependency in nineteen patients who had venous ulcers and "phlebographic evidence of incompetent perforating veins". There were eight normal controls. They used the 133 xenon washout technique in which a saline solution of the gas is placed in contact with the skin near the ulcerated area. The "tracer" diffuses into the skin and extends into the subcutaneous tissue using this method. Taking readings of this deposit in the skin at various intervals and under various conditions allowed them to assess blood flow in the skin but only in relative terms; quantitative measurements are not possible using this method.

Normally, in conditions of venous hypertension a spinal reflex detects pressures above 25 mm Hg. and causes a vasoconstrictive response and one would expect that patients with venous ulcers would have lower oxygen levels in the skin as a result. When a patient stands, the full effect of the weight of

the column of blood from the level of the heart would be noted and the constriction of the vessels activated. The moderate exercise of walking, the researchers noted, overcame the initial vasoconstrictive response in both the patients and the controls and perfusion of the skin increased in both groups. Although there were relative differences, they were not statistically significant. The control group on sitting had an average flow rate of 0.61 (range 0.35-0.80) and the group with venous hypertension showed an average of 0.46 (range 0.22-0.87) During walking the rate rose to an average of 0.96 (range 0.60-1.58) in the controls, and to 1.04 (range 0.49-1.46) in the patients. The researchers concluded that:

” the sustained increase in venous pressure observed in patients with chronic venous insufficiency did not affect the subcutaneous blood flow to the lower legs during walking” (p. 180).

They hasten to add that their findings do not imply that:

“decreased oxygen extraction due to diffusion blocks, elongated tortuous capillaries and increased diffusion distances might not be important in the development of venous ulcers”

but it clearly indicates that tissue perfusion is, at least during exercise, relatively normal.

In conclusion, it would seem to be clear that the microcirculation is disordered in a number of ways. These changes probably take a considerable time to occur and there may well be opportunities to intervene to prevent deterioration and, in some cases to prevent ulceration altogether. Interventions aimed at restoring the venous circulation to as near normal as possible, such as elevation of the leg, or the use of compression hosiery or bandaging to relieve the superficial effects of the abnormally high venous pressure would seem appropriate.

Chapter 3 The chronic illness trajectory framework

Introduction

“The very first endeavor to understand chronic illness through qualitative investigation originated in Grounded Theory’s ideas about life management.” Gerhardt continued, that it was with the publication of *Chronic Illness and the Quality of Life* in 1975 “...that the field of qualitative research on chronic illness was first put on the agenda of medical sociology” (1990, p.1153). Since its beginning in the 1960’s, grounded theory has been used by a number of researchers and a substantive theory of chronic illness has emerged. The trajectory framework is a “substantive theory about chronic illness, developed specifically to provide insight and knowledge about chronic conditions in general” (Corbin and Strauss, 1992, p. 10).

The trajectory framework was first considered for use in the present study when the researcher was doing exploratory work with student nurses and District Nurses. Coming from a very different community nursing background to them, a framework was sought that could sensitise the researcher to the possible approaches and concerns and indeed, perhaps give direction to the location of possible answers to the general questions that initiated this study: “What is it like to have a venous ulcer?, What are the key concerns of those who have them and those who manage their care?” Interest in the framework led to the few qualitative studies available in the literature on chronic illness and to grounded theory as a method of inquiry. During the process of data collection and analysis, the trajectory framework was found to be a useful tool in analysing and exploring the data. It was therefore adopted to help with the exposition of the findings. It has the benefit of spanning the disciplines of nursing and sociology and it is capable of encompassing the complexities of the experience of chronic illness and its management from the individual’s and the health professional’s perspective within the context of community based care delivery. Nursing models were considered for use but as they have been developed by nurses within the single discipline of nursing they lacked the scope required as they, by definition, focus on nursing “...for the purpose of

describing, explaining, predicting or prescribing nursing care” (Meleis, 1991, p. 167). The chronic illness trajectory framework, developed by Corbin and Strauss overcomes these constraints by focusing on the holistic experience of the client and on the work of all involved in the management of chronic illness.

The trajectory framework will be presented first of all from an historical perspective: the key concepts will be discussed in detail and the phases of the model will be introduced. The nursing model proposed by Corbin and Strauss(1992) will then be discussed before turning to an exploration and analysis of the usefulness of the model in the examination of chronic illness experience.

The development of the chronic illness trajectory framework

The chronic illness trajectory framework has an interesting history that began in the 1960's. The concept arose from an early study of Glaser and Strauss (1965) in which they examined the interactions of people involved in the hospital setting within the process of dying. Although the focus of their research was “awareness contexts”, that is, “what each interacting person knows of the patient's defined status along with his recognition of the others' awareness of his own definition” (p. 10), the concept of trajectory was present in the discussions of both diagnosis and prognosis. The researchers noted that key people, such as doctors, nurses and patients, held varying expectations about the certainty and anticipated time of death. In some areas death was expected to occur, if at all, within a definite period of time and survival beyond that point brought with it changed forecasts. Dying, as a process, was seen to occur over time. The importance of accuracy in determining the patient's location in the process came from the fact that the needs of the patient and the organization of work required of the hospital varied with his condition.

The second book, *Time for Dying* (Glaser and Strauss,1968) took as its central focus the temporal aspects of dying. Glaser and Strauss drew on their data gathered previously for the study of “awareness contexts” and supplemented it with data collected in ten hospitals in Italy, Greece and

Scotland. The “dying trajectory” was said to have the properties of duration and shape but neither was based upon purely physiological data:

“They are both perceived properties; their dimensions depend on when the perceiver initially defines someone as dying and on his expectations of how that dying will proceed. Dying trajectories themselves, then are perceived courses of dying rather than actual courses” (p. 6).

The organisation of work is based on these perceptions and therefore in turn affects the shape and phase of trajectories over time. There is a complex relationship between structure and function and these can be varied to accomplish specific tasks; an extra nurse, for example, might be brought into the ward to care for a patient with specific needs that could not easily be met otherwise. The experiential career of each participant in care will also affect the shape of the trajectory. A nurse, for example, unaccustomed to using the monitors in intensive care, might miss early warning signs of change that an experienced nurse would have picked up immediately and the delay might have an adverse effect on the shape the trajectory.

Status Passages (Glaser and Strauss,1971) was the first formal theory developed by the authors using the grounded theory method as set forth in *The Discovery of Grounded Theory* (Glaser and Strauss,1967). This theory was generated through “the comparative analysis of multiple substantive areas” (1971,p. v). The combination of trajectory and awareness concepts permeates this work: “Status is a resting place for individuals” but “a temporal dimension is implicit in all kinds of status” (1971,p.2-3). The shaping of a status is described in part, as being linked with certain types of awareness contexts which allow various agents to exert a degree of control required to manage the passage.

Shaping as a process to control the passage of a person was briefly described in *Time for Dying* (Glaser and Strauss,1968, p. 150, 163) and can be seen acting through the various awareness contexts discussed in detail in *Awareness of Dying* (Glaser and Strauss,1965), but in *Status Passage* (Glaser and Strauss,1971) it finds its fullest exposition. Later works include the term, but the description and its definition are found here: “The shape of a status passage is determined by combining its direction and temporality” (p. 57).

Shape refers to the trajectory of the person. Shaping is achieved through controlling: through prescribing the key aspects of the passage (p. 58), by organizing care in the hands of an authoritarian agent who might resort to closed awareness to maintain control (p. 62), through avoidance of completion of the passage (p. 64), through non compliance (p. 66), or through actions of an “incompetent or inappropriate agent” (p. 77) for example. For the person, the status passage between independent agent and patient, between well person and ill, is often an emergent one in chronic illness. It may lose its “open ended” and “innovative” characteristics as it enters the structural constraints of medical/nursing management and becomes a “chartered passage...set up by the duly authorized people of an organization, group or institution”(p. 86). It is the chartered nature of the passage that gives the person his career within the health care setting.

The theories of awareness contexts, of dying trajectory and of status passages have much to offer the nurse researcher. They each have the advantage of flexibility that comes from the level of generality of the concepts used. This degree of flexibility would be expected of the formal theory of status passages but it would normally be unexpected from the substantive theories of awareness contexts and trajectory of dying. However, Glaser and Strauss believe that the person who applies their substantive theories will, because of their level of abstraction, be able to adjust them to the specifics of the situation he wishes to improve and will have a level of control that comes from the number of general concepts in the theories and their “plausible interrelations” (Glaser and Strauss, 1968, p. 243). In short, the user of these substantive theories will have a general understanding about how the key variables might respond to manipulation; the user of the formal theory, of how they would be expected to respond.

The development of the chronic illness trajectory theory

Following these early studies Strauss began teaching a course on chronic illness to graduate students in 1971. The doctoral students in sociology and in nursing were “encouraged to undertake qualitative studies examining the

management problems associated with different chronic conditions" (Corbin and Strauss, 1992, p.11) and from these studies, over the years, Strauss was able to formulate an explanatory framework. As the framework was tested by nurses and found to be useful it was introduced in the book *Chronic Illness and the Quality of Life* (Strauss and Glaser, 1975). At that stage, however, "There were few concepts, and their integration and development were minimal" (Corbin and Strauss, 1992, p. 11).

It is in the second edition of *Chronic Illness and the Quality of Life* (Strauss et. al. 1984) that the two core concepts of the chronic illness trajectory theory are expanded and discussed in detail and the framework begins to take shape. The concept of "work", introduced in the *Time for Dying* (Glaser and Strauss, 1968) text receives considerable attention in the 1984 text. Originally considered in terms of tasks that need to be temporally ordered and performed if the patient is to receive appropriate care (p. 2 and 58), discussion is now extended by consideration of the implications of the work involved in managing chronic illness on the lives of the client and his family. The other core concept that underwent substantial refinement is that of trajectory. The original work of Glaser and Strauss explored a phenomenon that the researchers assumed would become more common in the future: dying from chronic illness in hospital. Their work from the outset drew on the experiences of patients with chronic illness trajectories although their attention was centred on the dying phase of those trajectories. Their research and that of their colleagues in the intervening period led to the development of the illness trajectory which referred "not only to the physiological unfolding of a sick person's disease but also to the total organization of work done over that course, plus the impact on those involved in that work and its organization" (Strauss et al., 1984, p. 64).

Having been previously presented through the course of its development to the sociological/research audience, the trajectory model was presented to the nursing profession in Britain in 1987 when Juliet Corbin (a co author with Strauss et. al. of *Chronic Illness and the Quality of Life*, 1984) addressed the delegates at the Nursing Times 2nd International Primary Health Care Conference in London. The following Spring, the *Nursing Times* published an

edited version of her paper (Corbin and Strauss, 1988a). Despite being expounded by the authors as the “one important model” to have emerged in the last twenty years of empirical study of chronic illness no subsequent references can be found in the nursing literature of Britain.

In the same year, their book *Unending Work and Care: Managing Chronic Illness at Home* (Corbin and Strauss, 1988b) was published. In this text, for the first time, one finds the trajectory model fully developed and explained and the core concepts defined. At a time of spiralling health care costs and when chronic illness was recognised as the most prevalent form of illness in all industrialised societies, this study of sixty couples managing a variety of chronic illnesses in the community setting was a natural progression from their earlier works. The authors explored the work associated with chronic illness and the management of that work within the context of the lives of its sufferers. The implications for health care provision that arose from this and earlier research were presented in their second book published in 1988: *Shaping a New Health Care System*(Corbin and Strauss).

In 1991 Corbin and Strauss submitted “The chronic illness trajectory framework: the Corbin and Strauss nursing model” to the nursing community in the *Scholarly Inquiry for Nursing Practice* (volume 5, number 3). The importance of this issue was noted from the outset by the editorial board and a special edition of this volume was published in 1992. It is the 1992 hardback edition that is referred to in this text. In that volume, the nursing model for chronic illness management based on the trajectory framework is first presented and then followed by critiques written by six clinical nurse specialists in chronic illness management. The six specialists had the remit of commenting on the appropriateness of the Corbin and Strauss nursing model to their area of practice. Overall, the reactions were favourable but there were some important criticisms raised. These criticisms will be discussed after the key concepts of the chronic illness trajectory framework and those specific to the Corbin and Strauss nursing model have been presented.

Key concepts defined: the chronic illness trajectory framework

The central concept of the model is that of **trajectory** which is linked with ideas of direction, movement, shape and predictability (Lubkin, 1990, p. 21). As has been seen from the definition of trajectory, it

“denotes not only the potential physiological development of an illness but also the work involved in its management, the impact of illness and the changes in the lives of the ill and their families that in turn affect their management of the illness itself” (Corbin and Strauss, 1988b, p. 48).

It encompasses the progress of a disease usually referred to as the “course of an illness” and in addition includes “...the active role that people play in shaping the course of an illness”. It incorporates the “...temporal phases, the work, the interplay of workers and the nonmedical features of management along with relevant medical ones” (Corbin and Strauss, 1988b, p. 34).

The doctor and nurse, the patient and family may each have a different **trajectory projection**, that is, an image of the likely course of the illness in the specific individual. The projections, based both on known facts and on perceptions and assumptions that may or may not be accurate, give rise to plans that are referred to as **trajectory schemes**. “The purpose of the trajectory schemes is to manage symptoms and control the course of the illness itself” (Corbin and Strauss, 1988b, p. 35). **Trajectory management** represents the process by which the illness course is shaped, through all its phases by the trajectory scheme” (Corbin and Strauss, 1992, p. 18) and includes for example, symptom control, the management of side effects of the regimen, giving information, mutual goal setting and making arrangements to support persons involved in goal achievement. The management of the trajectory path is accomplished through the shaping of the specific phase of the chronic illness trajectory.

The definition of trajectory schemes and projections will have a potent effect upon the individual and these are experienced in terms of biography. The concept of **biography** is a central one to the visions of how an illness and its management might impinge on the particular individual in his unique

circumstances. Biography, as used in this model, has three elements: **biographical time, conceptions of self and body**. Corbin and Strauss have coined the term “**biographical body conceptions**” to encapsulate these three interrelated concepts. “The combination of the three working together gives structure and continuity to who a person is at any point along the biographical time line”(Corbin and Strauss, 1988b, p. 52).

Biographical time focuses attention on the temporal aspects of experience in relation to the self. Each person has his own biography, a story of self through time. Individuals divide their experiences of life in temporal phasing and phrases such as “before I retired”, “once I was married”, “since the death of...” are common in everyday speech.

Conceptions of self are indeed complex and inextricably linked to biographical time. People change over time and formulations of self concept alter with these changes. The growth from one self definition to another flows along the person’s biographical time line.

Body, the third element of biography, is “...the medium through which conceptions of self are formed” (p. 53). The body provides the sensory and perceptual filter through which we experience our lives and is the physical presentation of the “self”. The social presentation of self occurs through performance and in the well person can demonstrate the harmonious blend of mind and body. Performance is made up of the capacity to perform an act and the appearance of that action: both may be diminished in chronic illness. Performance failures obviously have an impact on the conception of self and may form markers along the passage of biographical time: “I used to enjoy walking in the Lakes before this illness confined me to a wheelchair “ is an illustration of this fact: biographical time is linked in terms of before and after, the concept of self alters with the change from walker to wheelchair bound person and it is the body affected by the chronic illness that represents the performance failure.

All three components of biographical time, the conceptions of self and the body are woven into a single chain of evidence for the individual in sickness or health. It is in “**everyday life activities**” (Corbin and Strauss, 1992, p.19) that “persons live out the many aspects of their selves” and present themselves to society. **Reciprocal impact** described in the same source, is the consequence component of the trajectory framework and emphasises:

“...the complexity of management and the potential compounding of problems that can occur due to the interaction between illness, biography and everyday activities” (p. 19).

For the chronically ill whose daily routines are subject to performance decay or failure, or who have management regimens or symptoms that are intrusive, the work required to “normalise” can be great. The importance of successful management of a trajectory cannot be over emphasised because the very ego of the individual is invested in the skilled performance of key routines in his life (Goffman, 1959, p. 43) and chronic illness can threaten the person with nothing short of the loss of self.

Trajectory projections and schemes will change over time. Chronic illnesses are by nature long term and the individual's passage through an illness and his response to the treatment plan will vary. The **shape** of a trajectory is formed by the interaction of many factors including: the illness, the individual's unique response to it, biographical contingencies, the physicians and the individual's trajectory projections and trajectory schemes. (Corbin and Strauss 1988b, p. 43). Trajectory shapes have the properties of **variability** and **phasing**. Variability may be evident in terms of the form of the trajectory and its duration as well as in the nature of the work done. The phases give a trajectory its shape. The example below is a schematic of the trajectory projection of an acute wound.

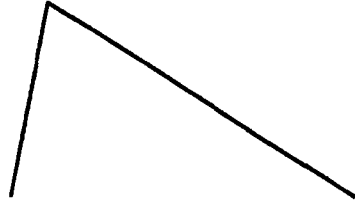


Diagram 22. Trajectory of an acute wound.

By contrast a chronic wound might be represented as below.



Diagram 23. Trajectory of a chronic wound.

Definition of phases

There are eight phases in the framework of Corbin and Strauss as presented in 1992. Some, for example, the crisis, acute, stable, downward and the dying “correspond to the physical and physiological status of the illness” (Corbin and Strauss, 1998b, p. 45). A **crisis** is defined as a life threatening phase. An **acute** phase is one in which active illness or complications requiring hospitalisation are apparent. A **stable** phase is just that: one involving remission or very slow change over time and which requires routine management. The **unstable** phase is one in which the chronic condition is “persistently out of control”. In this phase hospitalisation may be required but

often the individual is managed in his own home. The **downward** phase indicates deterioration which may be gradual or rapid. With regard to the **dying** phase it needs to be noted that it may occur as a direct result of the chronic illness but its inclusion in the framework does not indicate that a chronic illness is by nature a life threatening or a terminal one.

There are two other phases in the framework that require different types of work. The **pretrajectory** phase is a time of prevention; in this period health education work and safety work might be highlighted. Interestingly, this phase was present for the first time in 1992 and does not appear to have developed during the research of Corbin and Strauss. It emerges as a logical component of the framework but as it is an aspect of the model that is found to be problematic by more than one nurse researcher (as discussed below) it needs to be specifically commented upon. Similarly the **trajectory** phase is of interest. It emerged from the 1988 study of chronic illness management in the home and there it was described under the heading of “**the diagnostic quest**” (p. 23) where it was divided into three phases: the **prediagnosis** phase, the **announcement** phase, and the **post-diagnostic** phase(1988b). The contraction in the 1992 text of these three phases into the single heading of **trajectory onset** makes the application of the framework to clinical practice somewhat cumbersome because of the sheer volume of work and time encompassed by it. The trajectory projection and scheme may change numerous times in this period as the individual attempts to define the nature of the condition affecting him and decide whether or not medical intervention is indicated. Having come to this conclusion, the course from a personal trajectory projection to a medically defined one, that is, to one that rests upon a medical diagnosis, can be a lengthy and frustrating journey due to the vagueness of symptoms, the limitations of diagnostic technology, or the interests and expertise of the doctors concerned with care. The phases and their defining characteristics are summarized in table 5.

<u>Phase</u>	<u>Definition</u>
1. Pretrajectory	Before the illness begins, the preventive phase when no signs or symptoms are present
2. Trajectory	Signs and symptoms are present. Includes the diagnostic period.
3. Crisis	Life threatening situation
4. Acute	Active illness or complications that require hospitalisation for management.
5. Stable	Illness course/symptoms controlled by regimen.
6. Unstable	Illness course/symptoms not controlled by regimen but not requiring hospitalisation.
7. Downward	Progressive deterioration in physical/mental status characterised by increasing disability/symptoms.
8. Dying	Immediate weeks, days, hours preceding death.

Table 5. The phases of the chronic illness trajectory framework.

Source: Corbin and Strauss(1992) p.17.

The nursing model: application of the chronic illness trajectory framework

a) General approach

In applying the trajectory framework to nursing practice the authors of the model focused on four domains: the person, health, the environment and nursing. Their choice of domains is congruent with the views of many nurse theorists but their core concept and integrating focus, trajectory, is unique. The domains of the model will next be presented and then their method of applying the framework in nursing practice will be considered.

The **person** is viewed as an active participant in his ongoing care having both the primary responsibility for prevention and management. The context of chronic illness is the individual's life: his biography, his conceptions of self and his body. **Health**, viewed from the perspective of chronic illness, equates with maximising the quality of life of the individual. The central **environment** of chronic illness management is the home of the individual and should be perceived as the centre of care (Corbin and Strauss, 1988c, p. 46). The hospital and other health care facilities then become "backup resources to supplement and facilitate home care" (Corbin and Strauss, 1992, p. 20). **Nursing** has the ultimate goal within the chronic illness trajectory framework of helping clients "to shape the illness course while maintaining quality of life" and this dual goal is achieved through "supportive assistance" (p. 21). Primary prevention or the prevention of disease is the first function of the nurse but when this is not possible or fails, then it is the role of the nurse to provide the proper management of the chronic condition taking into account the biographical needs of the person and his performance of everyday activities. The "targets" of her care include the individual, the family, the community and society. The **nursing process** is the operational framework of providing supportive assistance. "The nursing process is an orderly, systematic manner of determining the client's problems, making plans to solve them, initiating the plan or assigning others to implement it, and evaluating the extent to which the plan was effective in resolving the problems identified" (Yura and Walsh, 1978,

p. 20). According to Corbin and Strauss (1992, p. 21) the nurse, of all the health professionals is the one best placed to assist the individual as, in their opinion, "only nurses have the skills, knowledge, and vision to organize and provide for the comprehensive and technologically complex care that chronically ill clients require."

B) Specific guidelines

The trajectory concepts are used in applying the nursing process (Corbin and Strauss, 1992, p. 21). The phases of the nursing process: assessment, planning, intervention and evaluation are present in the Corbin and Strauss model but they appear in a format that has been adjusted to accommodate trajectory phasing and the management tasks of chronic illness. The exposition below of the five steps of the process is based on the 1992 text cited.

1. Locating the client and family and setting goals

The first task of the nurse and client is to determine the management problem that brings them together. This problem will serve as the basis for goal setting. For the client with a wound/venous hypertension, it would involve determining why the decision had been made to seek professional help at this particular point. As the client's management problem will stem from the reciprocal impact of chronic illness, biography and everyday life activities, the nurse is advised to locate the client on all three dimensions. She would assess, for example, how the wound was interfering with the activities of normal living, with sleep or work. She would ask about the impact of the wound on the biographical body conceptions: what effect was it having on his life at this time and how his conceptions of himself and his body had changed since the development of the wound. She would explore how the experience of having a wound had influenced his social presentation of himself, his capacity to perform his usual roles and function and how his appearance as the person he thought himself to be, might have altered. The specific trajectory phase would next be identified and the trajectory projections and schemes of the people involved

would be considered. From this point, mutually determined management goals would be established. The goals would be phase specific and might be subdivided into client oriented objectives. All goals would be developed so that evaluation criteria were integral to them.

2. Assessing conditions influencing management

Continuing with the assessment phase of the nursing process, the nurse and client would review the resources that could influence their decision making in relation to management: the personal resources of money, time, energy, the nursing/domestic manpower available, the equipment needed and accessible, the setting of care, the motivation and ability of the client and key support people, and the community resources and facilities. As the past experiences of the client might have a direct bearing on his choices or preferences in the present situation, these too would need to be explored. In the case of the person with venous hypertension who had an open wound, the nurse would want to know if the person could bend sufficiently and in comfort to see the wound site, if he could apply the compression bandages/stockings unaided or with support from a person available in the home or neighborhood. She would want to discuss the person's views about self care and his feelings of confidence to continue as the primary caregiver.

3. Defining the intervention focus

Having made a thorough assessment of the key management problem(s) influencing the present approach, the client and nurse would be in a position to decide what action needed to be taken to reach mutually agreed management goals.

4. Intervention

The nurse and client would put the plan into action. The actions might take the form of the nurse being involved in the provision of direct patient care, or of health education, making arrangements for alterations to be carried out to

the home or adaptations to be made available within it. Referral to another professional might also be undertaken as appropriate.

5. Evaluation of the effectiveness of intervention

Progress towards goals would need to be measured when appropriate to evaluate the effectiveness of the interventions. Chronic illness can be very unpredictable and the attainment of a goal at one point in the trajectory may be overtaken by subsequent downward phasing. Similarly, present attainment might be of little consequence in the light of biographical change. Therefore, as in any application of the nursing process, the cycle will be repeated as necessary and interventions changed and evaluated as required.

The status of the chronic illness trajectory framework:the Corbin and Strauss nursing model

The chronic illness trajectory framework is a substantive theory of chronic illness but the nursing model proposed by Corbin and Strauss has not been systematically tested in clinical practice. The model, the authors state: "has had considerable application over the years by individual nurses and has been found to be effective in providing insight and guiding practice" but they caution: "Much work is still needed to develop it as a model for research, teaching and practice" (Corbin and Strauss, 1992, p. 15). Corbin and Strauss(1992) quote Meleis(1985, p.30) in expanding on their view of the relationship of theory to practice

"The primary use of theory is to guide research. Through interaction with practice, *guidelines for practice will evolve...Until* empirical validation is completed, theory could be given practical validation and could therefore be allowed to give direction to practice."

This practical validation must proceed carefully and Corbin and Strauss hope that the refinement of their model will be carried out through the continued interplay of research and practice. The Corbin and Strauss nursing model is presented as being thoroughly grounded in a research base of chronic illness but requiring "further clarification, elaboration and qualification...Think of this model as only the beginning..." (Corbin and Strauss, 1992, p. 102).

The model is therefore presented in the 1992 publication in order to generate discussion with clinical practitioners and not to direct practice. Since 1992 more nurses in research, teaching and clinical practice have referred to the model and begun to explore its usefulness in nursing practice and to develop it into a form that might one day direct practice. The responses of the six clinical experts, Hawthorne, Nokes, Rawnsley, Scott Dorsett, Smeltzer and Walker, whose work appears in the 1992 publication are next discussed and integrated with this material are other relevant studies and critical comments.

Model applied to cancer nursing

The first clinical specialist to comment, Diane Scott Dorsett, is a specialist in the care of clients with cancer. She takes immediate exception to the model because she interprets it as condensing "...the cancer experience into the time warp of symptom driven illness mediated by medical treatment until death occurs" (p. 13). Citing statistics that demonstrate five year survival rates from cancers, she asserts that a more appropriate theoretical model for her area of practice is **recovery**. Keeping with the ballistic analogy she states "...if illness is represented by the trajectory of a Scud missile, recovery is the Patriot" (p. 30). Recovery is characterised by "renewal and recuperation" and is defined as a basic human process whereby the individual adapts over time to changes in well being (p. 33). A basic difficulty she highlights is the variable nature and course of cancer. "Cancer" is a term used to embrace a variety of conditions and not all of them constitute chronic illnesses.

Whereas the nature of cancer might make it in some cases, an acute and temporary illness, this will not be the experience of all. Scott Dorsett's misunderstanding of the model leads her to reject the model on the grounds that it represents an illness oriented view (p. 37). She fails to see the individual at the pivotal point in the model. While not averse to using the term trajectory, she wishes to emphasise only the positive direction inherent in the recovery trajectory model.

The objections of Scott Dorsett lie partially in her philosophical stance and partly in her incorrect interpretation of the Corbin and Strauss model. Corbin and Strauss state that trajectories are uncertain and can only be graphed in retrospect (1992, p. 16). Whether one is on a trajectory of recovery or a chronic illness trajectory will only be known with hindsight. Recovery in terms of upward movement is present in the Corbin and Strauss model and considered from the perspective of maintaining the quality of life for the individual: it represents the goal of trajectory management (p. 18). The emphasis in the trajectory framework on the individual and the reciprocal impact of the illness, biography and everyday life, does not allow the individual

practitioner to choose a focus for the patient. The recovery model, however, forces him into a projection of renewal and recuperation because this view is held by the nurse. Recovery may or may not be a concept held by the patient and it will not always be appropriately held by the nurse. In the end, it is the patient's experience and not the nurse's model that matters and the Corbin and Strauss framework recognises this truth. The criticism that the focus is on illness in their model indicates a failure to appreciate the complexity of trajectory as defined in the model. Certainly without the illness there would be no chronic illness trajectory but the concept is linked to, not defined solely by the illness. This is made clear in the 1992 presentation that Scott Dorsett was given to comment upon.

The model applied to the cardiology patient

The misconception that the trajectory framework focuses on illness is not shared by other clinicians. Mary Hawthorne, the cardiology nurse specialist, for example, finds the Corbin and Strauss trajectory framework appropriate to her work in cardiac illness for the very reason that it moves away from the illness focus traditionally held in medicine and centres instead on the patient. Cardiac illness trajectories, she notes, are often partly managed by the use of hospital based technologies that reinforce "the medical paradigm of acute illness". The trajectory framework view removes "the artificial dichotomy between the patient's time-line(biography) and the illness trajectory and permits these acute/crisis episodes to be seen as important but small occurrences in the context of a lifetime" (p. 47). Hawthorne also finds the concept of shaping helpful as it accents the possibility of altering the experience by risk factor modification (p. 43).

The model applied to HIV/AIDS

Kathleen Nokes, a specialist in HIV/AIDS, draws attention to the problem inherent in the definition of the **trajectory onset phase**. As defined by Corbin and Strauss, the phase starts with the onset of symptoms(Corbin and Strauss, 1992, p. 17). HIV disease, she points out, begins long before symptoms

appear. By extension, though Nokes does not comment upon it, the pretrajectory phase does not fit the HIV/AIDS pattern of chronic illness either. During the **pretrajectory** phase there are no signs and symptoms but the illness course has begun and prevention of illness or even of progression, is not possible. As mentioned previously, the **pretrajectory** phase was not developed from studies of chronic illness but was introduced in the 1992 text perhaps to incorporate the preventive work of health care professionals and others. The problem of finding the individual's experience reflected in the definitions of the first two phases will occur in any illness in which there is a time lag between actual illness onset and the appearance of clear symptoms. Given the vague presentation of symptoms at the onset of many chronic illnesses, the definitions given by Corbin and Strauss simply are not adequate and will need further refinement. To be useful in managing the work trajectories of patients, the phases have to be logically and consistently defined and clearly separated.

The model applied to mental health nursing

Marilyn Rawnsley, a mental health specialist, underlines the particular difficulties inherent in using the model in her field. Firstly, she notes that "Symptoms and episodes in pretrajectory phase of major mental disorders,...are frequently recognized as such only in retrospect" (p. 61). The important aspect of this passage does not lie in the statement that trajectories can only be graphed in retrospect with which Corbin and Strauss agree. Here, Rawnsley has digressed from the Corbin and Strauss framework by equating the **pretrajectory** period with the prodromal period when evidence of illness is present and assessment is possible but clinical diagnosis has not been determined. In defining the initial phases differently to that given by Corbin and Strauss, she may be leading the model toward a possible resolution of its difficulties in phases one and two. She continues by stating that in the **pretrajectory** phase, as she uses the term, the symptoms are often given "a less pernicious diagnosis" and appear later as a "disguised prelude"(p. 63).

Towards a clarification of terms

Rawnsley does not elaborate on her alterations to the framework. However, following on from her revised definitions of the first two phases, a resolution to the problems presented becomes apparent. If the **pretrajectory** phase were to be amended to encompass the prodromal period when illness was present but symptoms and signs had yet to develop into a pattern of known significance, it would become part of the trajectory and would run from illness onset to diagnosis. Returning to the term used in the 1988 text it could perhaps be labeled the **prediagnostic** phase. With this aspect of the diagnostic quest removed, the next phase could be termed the **diagnostic** phase during which formal identification of the trajectory would be made.

To cover the period prior to illness onset, an additional phase, termed the **preventative** phase could be added to the model. It would, by definition focus attention on the work involved in *avoiding the onset of a trajectory associated with illness*. Of course, not all chronic illnesses can be prevented given the present level of medical knowledge, but increasingly the onset factors are being identified and prevention is becoming more and more possible.

Additional problems in applying the model to mental health work

Mary Rawnsely, in her critique, indicates a core difficulty in applying the model as it stands, to the field of mental illness. The concept of **biography** is usually viewed as the context of the illness experience when chronic physical disorder is discussed. However, conceptions of self over time “may be the source of the illness” and in some, the biography itself is the location of illness causation(p. 62). In a real sense, one could say that it is the reciprocal impact of biography on society that defines these illnesses.

Rawnsely, despite these difficulties finds the model useful. The emphasis on the **supportive assistance** function of the nurse strikes a particular chord in the mental health field where counselling, teaching, monitoring and coordinating are key elements. She also sees the possible

value of the model in assisting practitioners to view old problems in a new light, perhaps generating new research questions in the mental health field. The model, she feels, has great value as a sensitising agent.

The model applied to multiple sclerosis

Suzanne Smeltzer indicates that the application of the specific guidelines given by Corbin and Strauss is very easy to relate to a patient with progressive multiple sclerosis or one in whom physical disability is a problem. She thinks that the model lacks guidance to the professional, however, in relation to a patient in remission. According to the Corbin and Strauss model, the nurse, in fact, only has a role when a specific management problem brings her together with a patient: the patient is the key figure and the nurse, the person who renders supportive assistance that is goal directed and phase specific. Viewed in this manner it could be said that the model actually does give guidance to the professional in placing the patient at the center and in control. Smeltzer notes that the "focus of the trajectory framework on chronic illness as a process in time rather than as a single point in time"(p. 87) assists the professional in developing insight across the phases of exacerbation and remission.

She mentions briefly that, until recently, diagnosis has been made by the process of elimination. Even in 1992, with the increased availability of magnetic resonance imaging technology that can demonstrate demyelination of the nerves, the resulting evidence is not definitive (p. 77). Despite these facts, she does not concentrate on the problems of the patient moving from the prediagnostic to the diagnostic phase. This transition can indeed be an arduous and lengthy one for most victims, not simply because of the possible time lag between illness onset and the development of recognisable symptoms, but rather because of the vague and varied manifestations of the illness over time that make incorrect determinations of the trajectory so likely.

Stewart and Sullivan (1982, p.1398-1404) examined the prediagnosis behaviour of 60 patients between 1975-1977 who had been diagnosed as having multiple sclerosis. They found, as was noted in the introduction, that on average it had taken five and a half years for each person to achieve an accurate medical diagnosis and during this phase, which they defined as the

period from "...the time of contact with medical professionals but without authoritative legitimization for the sick role" (p. 1398), the individuals moved through three distinct phases. During the first phase, the "nonserious phase" the symptoms were considered to be simply minor ailments of a transient nature. Variations in health were attributed to stress, "getting older", or being run down for example. Self treatment was the normal response and included actions from changing ones routine to taking over the counter medications. During the "serious phase" when the symptoms changed to be more intrusive, the individuals came to reject their original views and saw their symptoms as indicative of acute physical illness that could be both easily diagnosed by the doctor and cured. It was during this period that significant personal stress was experienced because their expectations were not realised: the symptoms were too vague and diagnosis was not at all straightforward. Repeated consultations led to various incorrect diagnoses being made and a variety of treatments being prescribed. The impact of this period in personal terms was immense; the sufferers came to distrust their doctors and to suffer considerable stress from treatments that failed to achieve symptom resolution. Over time, family and friends came to view the patients as "hypochondriacs and malingerers" (p. 1401). Such was the distress of this period that the correct diagnosis, achieved in the "diagnosis phase", produced positive emotional reactions because at last they knew what they were dealing with and at last they had proof for their families and friends that they were not suffering from imaginary illnesses. Stewart and Sullivan's study highlights the iatrogenic nature of consultation during this process. Usually associated with treatment, their study found it linked with the ambiguous nature of the social relationship between patient and doctor.

Smeltzer(1992) will not necessarily see this period as her work begins upon accurate medical diagnosis and is based in a hospital setting. The hidden nature of the prediagnostic period and the distress it causes is of concern to the health professional; the stress caused by the lack of definition of the illness has considerable negative consequences. It is through the examination of the illness experience, using grounded theory approaches and a model that can accommodate the realities of chronic illness, that the nurse

gains the awareness needed to appreciate what “supportive assistance” might mean to a patient group. Perhaps the raised awareness of the nurse in primary care could ameliorate the prediagnostic trauma suffered by so many of these patients.

Hainsworth and colleagues (1993, p. 9-13) presented a single case study of a woman with multiple sclerosis and they explored her experience of chronic sadness throughout her trajectory. Through their use of in depth interview material, the reader has the opportunity to see the impact of the chronic illness trajectory on one woman’s biography over time and is allowed to enter into her very personal world of meaning. Again, the advantage and necessity of using wider frameworks and research approaches grounded in data is appreciated here.

The model applied to diabetes mellitus

Elizabeth Walker is the final nurse specialist to comment on the nursing model in the 1992 text. She finds it easy to use and in applying it to two hypothetical patients demonstrates some of its strengths in the nursing care of patients with chronic illnesses. Firstly, she notes that its focus on chronicity helps the nurse to look beyond the immediate state of the glycaemic levels of the person and to take a more comprehensive view of care. Secondly, she finds the application of many of the trajectory concepts helpful in data collection and in mutual goal setting. Concepts such as trajectory projection, reciprocal impact, biography, which are not found in other models are very helpful in her setting.

She emphasises the importance of further development and clarification of the model to make it more accessible to nurses in general. In particular she points to the need to “translate” the framework for clinical use. In this observation she points to one of the next stages in the model’s development: the major concepts will need to be operationally defined. Of interest in this respect is the fact that Walker is one of a faculty group of nurses who have gone on to work on this progression and whose work was subsequently published in the *Scholarly Inquiry for Nursing Practice* in 1993 (Robinson et al. 1993).

Summary

The 1992 publication of their nursing model marked the beginning of a new phase in the dialogue between Corbin and Strauss and the nursing profession. The majority of the clinicians invited to comment on the model and its relevance to their nursing practice responded positively. However, the relatively few references in the nursing literature to the model indicate that few nurses have become aware of it or have been attracted to it. There are many possible reasons for this lack of engagement with a model that is soundly grounded in research and which has such a valuable focus.

The origins of the model mark it as essentially non-nursing territory. At the time when the original research was being conducted in the mid nineteen sixties, nurses were more focused on the development of nursing theory. Our early theorists held our attention as they expounded their views of nursing and it is perhaps reasonable to view this time as one of introspection when we concentrated more on our professional role and functions.

During the early phases of the trajectory framework development, few nurses would have been exposed to this literature from an allied field unless they had been undertaking advanced programmes in universities and probably in disciplines other than nursing. In Britain, the evolution of non university based general nursing programmes that have included the sociology of health and illness began with Project 2000. Given the wealth of material to select from and the fact that such selections are limited by the knowledge of the nurse tutors making the choices, it is not surprising that the trajectory framework and the Corbin and Strauss nursing model have remained relatively unknown.

When Corbin and Strauss presented their framework in London in 1987 the vast majority of nurses were still being trained in the pre Project 2000 framework in which community experience, if present at all, could be a token gesture. The emphasis then was on the nursing care of patients in acute care, hospital settings and the significance of the Corbin and Strauss model would not have been generally apparent to the profession. It is a relatively recent phenomenon that we have become aware of chronic illness as the major health challenge of our time and of the financial costs associated with it.

The trajectory framework is a model for a mature profession; one needs to feel professionally confident as well as educationally and experientially prepared in order to relinquish the nursing models that, although avowedly patient centred, have placed the nurse in such a position of power and control. It is in the community setting where nurses are guests in patients' homes, or the obvious partners in care in the surgery based services for chronic conditions that "supportive assistance" is most likely to flourish.

The model has great potential value to nursing and as a guide to the researcher in the area of chronic illness management it has much to offer in terms of sensitising and focusing attention on the wider and most essential aspects of health care.

Chapter 4 Methodology

Introduction

This qualitative study utilised the grounded theory method developed by Glaser and Strauss. "Grounded theory is a general methodology for developing theory that is grounded in data systematically gathered and analyzed" (Strauss and Corbin, 1994, p. 273). It was an appropriate method for this study for three interrelated reasons: firstly because there is limited research to guide the nurse in this area of professional practice. Stern (1980, p.20) stated that the strongest case for the use of the grounded theory method could be made "...in investigations of relatively uncharted waters, or to gain a fresh perspective in a familiar situation" and in this study both conditions could be said to be present. Venous ulceration is a common problem and it is managed routinely by nurses but there is little nursing research to guide practice. Secondly, it was suitable because the research focus of this study was not to answer a specific question but to explore a substantive area and to discover what the main concerns were of those involved and to find the core processes that resolved them (Glaser, 1992, p.22). Finally, this method was adopted because of the desire that whatever emerged would be useful information with a high probability of guiding clinical practice. Bryman (1988, p.84) described this as one of the advantages of the grounded theory approach of Glaser and Strauss:

"...it allows theory to emerge from the data, so that it does not lose touch with its empirical referent; it provides a framework for the qualitative researcher to cope with the unstructured complexity of social reality and so render it manageable; and it allows the development of theories and categories which are meaningful to the subjects of the research, an important virtue if an investigation is meant to have a practical pay-off."

There is an abundance of quantitative research available on the subject of leg ulcer healing and management. However, nurses and doctors need more information than this if they are to assist their patients in their responses to illness. Bury (1988, p.1) contends: "A sound, effective and ethical approach to chronic illness must lie in awareness of and attention to the experiences, values, priorities and expectations of patients and their families." Medical approaches and quantitative methods are not appropriate in themselves; they

must be supplemented with an awareness of how the illness and its management influence the life of the individual concerned. Strauss and his colleagues, (1984, p.16) in discussing the impact of chronic illness on the quality of life emphasise that such diseases are “long term, uncertain, expensive, often multiple, disproportionately intrusive, and they require palliation, especially because they are ‘incurable’”. In order to deal with the problems faced by the individuals concerned, the health professionals must understand far more about their patients than mere medical facts.

The needs of those with chronic illnesses have been poorly addressed by existing positivist approaches. Morse (1989, p. 20-21) argues that in order to prepare nurses for this area of work we need not add fictitious literature to our reading lists; we need only to add the “rich descriptions of what it is like to be sick or, for example, suffering with cancer pain, or altered body image; what it is like to be a patient...” It is the qualitative studies, she argues, that provide a meaningful background to nursing education and care. The qualitative approach, she contends, “...may provide the theoretical framework or identify variables, hypotheses, or theory to be tested in subsequent research....identify new paradigms or directions of inquiry” (p. 20).

The views of Morse echo those of Glaser and Strauss (1967) who discussed the importance of developing research methods that would generate and not simply verify, theory. When they looked at the “jobs” of theory in sociology, they stated that, among other functions, it should:

“enable prediction and explanation of behavior....be useful in practical applications--prediction and explanation should be able to give the practitioner understanding and some control of situations...to provide a perspective on behavior...Theory that can meet these requirements must fit the situation being researched and work when put into use”(p. 3).

Qualitative studies have added much to nursing that is helpful in terms of chronic illness care. Qualitative research rests on “seeing through the eyes of the people you are studying...it entails a capacity to penetrate the frames of meaning with which they operate”(Bryman,1988,p.61). Through qualitative

studies the personal meaning of chronic illness as lived in the context of unique biographies is seen.

There have been a small number of quality of life studies undertaken in recent years on patients with "leg ulcers" or "venous ulcers" but only one has approached the research question by using qualitative methods of inquiry. In addition there is a single case study reported by Wise(1986). Her description of one elderly and isolated woman with a leg ulcer appears to have had an immeasurable effect on nurses caring for this client group. The description of the patient is one that includes depression, self neglect, alcoholism and the need to maintain social contact that leads her to interfere with her wound so that it remains open. This unique picture of the socially isolated older woman who interferes with her wound appears to have become a nursing myth: it is a commonly held view among the community nurses interviewed by Ertl (1992, p. 550) and it was found repeatedly during interviews of nurses for this study. Interestingly, the overall impression given by Wise closely resembles that given by Browse, Burnand and Thomas(1988, p. 412) which was quoted earlier.

There are only a few examples of quantitative approaches to the quality of life and some of the more important will be discussed. Flett and his colleagues (1994) explored the psychosocial aspects of chronic leg ulceration in a sample of fourteen elders in New Zealand. They administered a battery of psychological and health measure tests and found that when compared with controls, those with leg ulcers reported more pain ($p<0.001$), more health worries ($p<0.01$), showed lower levels of self-esteem ($p<0.001$) and higher levels of negative affect ($p<0.01$). Interestingly, the research utilised the revised UCLA Loneliness Scale, a "closeness of relationship" scale and one measuring the satisfaction experienced from relationships and found that these patients were as socially integrated as the controls. They concluded from their findings that:

"...the results do not support the claim that the frequent recurrence of leg ulcers or their inability to heal somehow reflects an attempt by lonely, socially isolated elderly patients to maintain daily contact with health care attendants."(p.190).

The small scale nature of this study of fourteen patients and fourteen controls does not detract from its value in contradicting what seems to have become an internationally held professional myth about the nature of these patients. This work is a very useful piece of research, and as they suggested, it should be a springboard for further research. Their results raise important issues but in order to improve the situation for the sufferers, the reasons for some of these findings need to be further elucidated through qualitative approaches. For example, it is not known why these patients have more pain, whether it is related to the ulcer, to other pathology, to activity, or to the nature of dressings and bandages used and their chosen research approach cannot clarify these areas.

Franks and his colleagues at Charing Cross and Westminster Medical School(1992) studied the quality of life of 168 patients during venous ulcer treatment with the four layer compression bandage system at local community clinics. They employed two data collection tools, a "standard questionnaire" and a self rating scale of distress which they state is "a well validated measure of psychiatric morbidity" (p. 182) and they administered these twice, twelve weeks apart. The researchers state that there were significant reductions overall in anxiety ($p<0.001$), depression ($p<0.001$) and hostility ($p<0.001$). They also noted significant differences in depression between those whose wounds were healed and those whose ulcers remained open($p=0.006$) and in hostility ($p=0.013$). Pain was also decreased significantly ($p<0.001$). As no controls were used it is difficult to attribute all these positive gains entirely to attendance at community ulcer clinics. Again, the results are tantalising: why are the patients so hostile, for example? Is there something in their previous management that has led to increased levels of hostility? Are these levels unusual when compared to the general patient population? With regard to the pain, did it decrease due to ulcer healing, or lower anxiety, or to adequate analgesia? The reader is left wondering and hoping for a qualitative study to follow up these very enticing findings.

The more recent work by Hyland and Thomson (1994) produced a quality of life questionnaire for patients with leg ulcers. They used focus groups to gain qualitative information about the experience of 22 ambulatory patients who

were “opportunistically recruited” (p.295) and analysed their contributions to define four categories: pain, restriction of activities, mood and feelings and ulcer preoccupation and treatment. They subsequently developed a 54 item questionnaire which they piloted on a further group of 33 patients with leg ulcers. There were extensive revisions of the instrument before it was administered to a further fifty patients with leg ulcers. Their findings are of interest and again, intriguing to the qualitative researcher. There was no attempt to determine the types of ulcers the patients had although differences in response might be expected from the impact of various pathologies. Items that made their way into the questionnaire are of interest but they lead to more questions. For example, getting on or off a bus is mentioned in the questionnaire but the nurse needs to know the significance of this item to the patient if it is to be useful. Similarly: “I take pain killers for my ulcer”, another item, begs the questions of what pain, its nature, how effective the analgesia is, with what side effects and in what ways does the pain interfere with a person's biography?

Hamer, Cullum and Roe(1994, p.99-101) examined 88 patients' perceptions of their chronic leg ulcers in a quantitative way by gathering data on demographics, mobility, feelings and knowledge about the ulcer. They also administered the Nottingham health profile, the hospital anxiety and depression scale, the short McGill pain questionnaire and the locus of control scale. A control group of 70 people without ulcers was also included in this study. Ulcers were traced and photographed and Doppler measurements of the ankle/brachial index were obtained to determine the degree of arterial involvement. Details of the dressings, medical history and medications were taken. The results show that pain was rated as the worst thing about having an ulcer (37.5%), followed closely by restrictions to mobility (30.7%), inconvenience of dressings(10.2%), exudate(8.0%), and worry about healing(3.4%). Again, findings that require further exploration to be of practical clinical use and to make a difference to the lives of patients cared for by health professionals emerged and await qualitative elaboration.

The one nurse researcher to explore the quality of life issues from a qualitative perspective is Walshe(1995). She has provided perhaps the best insights available in the literature to date. In her small qualitative study of thirteen patients she explored their experiences of venous ulceration through unstructured interviews. Her approach was in reaction to the quantitative researchers who:

“fail to allow the experience of those suffering leg ulceration to shape their investigations. Most make assumptions...about the data to collect using specific tools or measures. These strategies could potentially exclude important experiences whilst emphasizing others unjustifiably”(p. 1094).

Her study emphasises the importance of the control of pain for this group of patients and this finding will emerge strongly in the present study. Because of her approach, she was able to report the patients views, describe them accurately and give conditions under which symptoms were worsened, such as during treatment. She also reported the patients' problems with mobility, with embarrassment from wound discharge and the inadequacy of coping mechanisms to deal with this aspect, difficulties with personal hygiene due to dressings, and the problems of getting a good night's sleep. She was able to describe how these patients coped under the distressing experiences of living with their venous ulcers(p.1098). In short, her chosen strategy provides information that is embedded in the personal experiences of the patients and which can usefully be studied by nurses and doctors to gain an appreciation of the impact of the condition on the personal lives of the patients.

Origins of grounded theory: the philosophical base

“The origins of grounded theory are derived from ethnography and symbolic interactionism. From ethnography, grounded theory has acquired interview methods, participant observation and the incorporation of other sources of information such as patient records. But most significantly, the influence of symbolic interactionism gives grounded theory its distinctiveness as a method” (Morse and Johnson, 1991, p. 4).

Symbolic interactionism as developed by Blumer is based on three premises:

"The first premise is that human beings act toward things on the basis of the meaning that the things have for them...The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters" (Blumer, 1969, p. 2).

A human being viewed within this framework is an actor, not a being acted upon. Blumer argued against the ascription of human action to initiating factors such as motives, attitudes, needs, status demands, role requirements. In contrast, he proposed that man, by the process of self-indication, makes an object of what he notes, gives meaning to that object and responds on the basis of that meaning. The person observes his world and constructs his action (p.15). The methodological stance of symbolic interactionism is "that of direct examination of the empirical social world" (p. 48) with the purpose:

"...to gather data through careful and disciplined examination of that world; to unearth relations between categories...to formulate propositions...to weave such propositions into a theoretical scheme" and to test these by "renewed examination of the empirical world" (ibid.).

The grounded theory method is directed towards accomplishing these goals. "Grounded theory allows the relevant social organization and sociopsychological organisation of the people studied to be discovered, to emerge—in their perspective!" (Glaser, 1992, p. 5). It is essentially interpretive work and "interpretations *must* include the perspectives and voices of the people whom we study" (Strauss and Corbin, 1994, p. 274). However, individual researchers bring varying perspectives to bear on the data; the data is filtered through each person's perception of the world. Strauss and Corbin (1994, p. 276) note that the researchers who use the grounded theory method will have been influenced by "contemporary intellectual trends and movements," and whereas the method will remain unchanged, the *analysis* will alter as "additional ideas and concepts suggested by contemporary social and intellectual movements..(enter) analytically as conditions into the studies of grounded theory researchers." They take the view that all interpretations are temporally limited (p.279) and therefore all resulting theories essentially fluid.

How then is the other's world of meaning to be explored and accurately reflected in theory? The problem is compounded by the fact that, as Blumer (1969 p.182) remarked, most concepts that could be used to represent the experiences of people are vague and imprecise; they could introduce "...a gap between theory and empirical observation". Blumer advocated "...improving the kind of observation that has to be made to handle the problems represented by our abstract concepts" and "...an enriching of experience which will make possible for observers to form more dependable judgment in those observations which give us trouble." He concluded that concepts would eventually become less imprecise as "observation becomes grounded in fuller experience." (p. 182) The essential process component of the grounded theory method, constant comparison, aims at achieving this end.

Origins of grounded theory: historical base

Grounded theory was developed at a time when the emphasis in social research was on the verification of theory rather than on its generation. The gap between theory and empirical research was one that was not being bridged under these circumstances. Moreover, there was evidence that logically deduced theories based on ungrounded assumptions were leading researchers astray in the pursuit of the advancement of their field of study and that there was "the opportunistic use of theories that had dubious fit and working capacity" (Glaser and Strauss, 1967, p.1-4). Morse and Field(1985) provide examples of this problem in nursing and conclude that:

"Deductive theory, building as it does on previous knowledge and research, is less likely to disturb the prevailing paradigm unless competing tensions become strong" (Field and Morse, 1985, p. 4).

Glaser and Strauss in developing the grounded theory method wanted to redress the balance. They wished to stimulate theory generation because they saw clearly "that the masters have not provided enough theories to cover all the areas of social life" and moreover:

“...some theories of our predecessors, because of their lack of grounding in data, do not fit, or do not work, or are not sufficiently understandable to be used and are therefore useless in research, theoretical advance and practical application” (Glaser and Strauss, 1967, p.11).

What they advocated was not the neglect of the “masters” but rather the emulation of their work in generating theories: the gap between theory and empirical research that was not being narrowed by the improvements in method for testing theory could be eliminated by the development of theories grounded in social research.

The type of theory generation they suggested was, however, based on a new method. In their 1967 work they presented their grounded theory method and compared and contrasted it with the two other approaches. First, they examined the approach of the researcher who converts qualitative data into a quantifiable form in order to test a hypothesis. Next they submitted the case of the analyst who “wishes only to generate theoretical ideas—new categories and their properties, hypotheses and interrelated hypotheses” (p.101). To the latter, analysis after coding is too confining because by the nature of his approach he is constantly “redesigning and reintegrating his theoretical notions as he reviews his material.” As a result, he “merely inspects his data for new properties of his theoretical categories, and writes memos on these properties” (p. 102). The new approach to the analysis of qualitative data which Glaser and Strauss suggest combines the two previously presented approaches; by the use of constant comparison the grounded theory method builds upon the coding of the first and the analytical approach of the second:

“The purpose of the constant comparative method of joint coding and analysis is to generate theory more systematically than allowed by the second approach, *by using explicit coding and analytical procedures.*” (p. 102)

The method will next be presented and then discussed as the procedures apply to this study of the personal and professional implications of venous ulceration.

Grounded theory method

“The grounded theory approach is a general methodology of analysis linked with data collection that uses a systematically applied set of methods to generate an inductive theory about a substantive area” (Glaser, 1992, p.16).

The researcher begins the process by being interested in a substantive area rather than having a research problem; to begin with a specific focus is to force the data. Rather, the grounded theorist begins with an open mind and waits to discover what the core process or issue is in the area and what resolves it (p. 22). It is the subjects’ problems that emerge and not the researcher’s preconceived interests that drive the process(p. 23).

The grounded theory method is an inductive one. As data collection and analysis are carried out together, it is obvious that the method includes deductive reasoning, however, the deductions are based on information that arises from the data. Deductive elaboration in this method is referred to as “conceptual elaboration” to differentiate it from “logical elaboration found in deductive hypothesis testing research” (Glaser, 1978 p. 40). Conceptual elaboration, Glaser continues to explain, is a matter of systematically deducing theoretical possibilities and probabilities from the data. Hypotheses are formed as a result but these are not proven except in the sense that *if* they continue to fit the emerging theory they are retained and continue to direct further data collection and analysis.

Theoretical sampling

As has been said, analysis is linked with data collection and in fact the analysis gives direction to and controls the ongoing sampling:

“Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser and Strauss, 1967, p. 45).

Rather than following a predetermined plan for data collection, so common when the researcher is attempting to test theory, the data collection in

the grounded theory method is subject to ongoing adjustment to ensure relevance to the emerging theory.

The initial decisions about the sample are simply based upon the criterion of theoretical relevance. Codes arise from the raw data from the outset by the use of the process of constant comparative analysis and it is the codes that give direction to further data collection. In turn this leads to further theoretical development of the codes:

“Theoretical sampling on any code ceases when it is saturated, elaborated and integrated into the emerging theory. This process produces cumulatively intense theoretical sensitivity into one’s data as the integrative matrix of the emerging theory grows denser” (Glaser, 1978, p. 36).

The researcher does not know where the codes will lead and cannot pre-plan her data collection; the aim is to develop the categories and their properties as fully as possible and by this process to see relationships between categories which will lead eventually to the discovery of the theoretical framework embedded in the data.

Grounded theory is an inductive method; “...a theory is induced or emerged after data collection starts”(Glaser, 1978, p. 37). Deductive work is used in the service of further induction. The data give rise to codes and the researcher uses deductive reasoning to determine the next group to use as a comparison. *Hypotheses are formulated in this process but not at the beginning* as would be the case in deductive methods. Hypotheses arise from emergent connections and they are either supported or refuted by subsequent data collection and analysis:

“Theoretical sampling is...used as a way of checking on the emerging conceptual framework rather than being used for the verification of preconceived hypotheses. Comparisons are made continually between kinds of information to generate qualifying conditions, not disprove hypotheses” (Glaser, 1978, p. 39).

The initial group for the research is chosen for its theoretical relevance and subsequent groups are selected on the basis of the deductive reasoning that their inclusion will assist in the development of the emerging categories and their properties:



"The researcher chooses any groups that will help generate, to the fullest extent, as many properties of the categories as possible, and that will help relate categories to each other and to their properties" (Glaser and Strauss, 1967, p. 49).

In the process of ongoing inclusion, the rules of comparability that are found in verification studies are lacking. The important feature of the groups chosen is that the "data apply to a similar category or property." and not that the groups are similar. Like and dissimilar may thus be compared and in the process yield important information regarding qualifying conditions under which categories and properties vary" (Glaser and Strauss, 1967, p. 51).

The constant comparative process gives direction to the ongoing decisions regarding data collection but it is important for the researcher to select ongoing groups with a view to the "scope of population and conceptual level" (p. 52). The theory developed in this study could have been confined to the situation of people with venous ulcers cared for by District Nurses for example. Ongoing data collection could have included other groups of District Nurses or different groupings of their patients. This decision would have resulted in the simplest level of theory development. Instead, ongoing data collection was done on different types of nurses and on different medical personnel, general practitioners and consultant dermatologists, so that the resulting theory is at the higher conceptual level than might have been the case and this illustrates the point made by Glaser and Strauss that : "The scope of a substantive theory can be carefully increased and controlled by such conscious choices of groups" (p. 52).

Grounded theory: stages

There are four stages to the method; as stated by Glaser and Strauss (1967, p. 105) they are:

- "(1) comparing incidents applicable to each category,
- (2) integrating categories and their properties,
- (3) delimiting the theory, and
- (4) writing the theory."

The first three of these stages will be discussed in turn. There will appear to be considerable overlap between the stages because these divisions are

artificial in a process that involves the interplay of data collection, simultaneous analysis, theoretical memo writing, ongoing decisions about further sample selection, the refinement of categories, the constant movement towards the emergence of core categories and their development through selective coding.

Comparing incidents applicable to each category

When the researcher enters the area of interest the primary focus is noting the incidents that are occurring and "...asking of the data the neutral question 'What category or property of a category does this incident indicate?'" (Glaser, 1992, p. 39). Each incident is coded into as many categories of analysis as possible; this process is known as *open coding*. By constantly comparing new incidents with previous ones and by looking for similarities and contrasts, categories and their properties emerge. Comparing incident with incident has:

"...the purpose of establishing the underlying uniformity and its varying conditions. Both the uniformity and the conditions become the generated concepts and hypotheses" (Glaser, 1978, p. 49).

Memoing is an integral part of the constant comparative process and of the discovery of the core category. By memo writing the analyst is able to capture the insights and theoretical notions that emerge from reflecting upon the data. Glaser refers to the writing of theoretical memos as the *core stage* of generating theory; he says: "the bedrock of theory generation, its true product is the writing of theoretical memos" and he defines them as: "*the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding*" (Glaser, 1978, p. 83). Memos become a means of both fracturing and reconnecting the data in meaningful ways that support grounded theory generation.

Integrating categories and their properties

The initial units of analysis in the constant comparison method were incidents. These comparisons gave rise to concepts and categories.

Continued use of the constant comparison method leads to incidents being compared "...with properties of the category that resulted from initial comparisons of incidents"(Glaser and Strauss, 1967, p. 108). Because "Open coding carries with it verification, correction and saturation phenomenon" (Glaser, 1978, p. 60), the initially numerous codes become integrated as the researcher begins to see which ones "fit" and capture the data correctly:

"Thus the theory develops, as different categories and their properties tend to become integrated through constant comparisons that force the analyst to make some related theoretical sense of each comparison" (Glaser and Strauss, 1967, p. 109).

Delimiting the theory

The theory becomes delimited in two ways: by reduction and theoretical saturation. Reduction comes from the discovery of underlying uniformities and the reformulation of the original categories into a "smaller set of higher level concepts" (Glaser and Strauss, 1967, p. 110). Theoretical saturation refers to the situation whereby no additional data are found that lead to category development. The delimitation of the theory is an ongoing process; as the theory develops subsequent modifications become less frequent and have the effect of clarifying the logic and reducing the theory. Through the ongoing use of the constant comparative process, the core category emerges and the researcher is able to move from *open* to *selective* coding which further delimits the theory. The core category is:

" the main theme, ...the main concern or problem for the people in the setting, for what sums up in a pattern of behavior the substance of what is going on in the data, for what is the essence of relevance reflected in the data ..." (Glaser, 1978, p. 94).

and once found it becomes the focus of further data collection and analysis.

The core category

Glaser(1978, p.95-96) provides criteria for determining whether a category is in fact, the core category of a study. To qualify, it must be:

- a) central: "It indicates that it accounts for a large portion of the variation in a pattern of behavior"
- b) "It must recur frequently in the data" demonstrating that it is a stable pattern.
- c) Because it is so prevalent and related to so many other categories it takes longer to saturate than other categories.
- d) It is easily seen that it is related to other categories; "It relates meaningfully and easily"
- e) It has "grabbing implication for formal theory"
- f) It has "carry through" which means that it assists the analysis by its "relevance and explanatory power"
- g) "It is completely variable...conditions vary it easily"
- h) "It explains itself by its own variation" because it is "a dimension of the problem"
- i) By its presence it prevents other categories from assuming core status thus protecting the study from the researcher's interests/bias, and from the dangers of deductive elaboration.
- j) Simply because of its "grab and explanatory power" the researcher begins to see it everywhere occurring.

Once the core variable is discovered, selective coding, that is, the coding of only those variables that relate to it, begins and this restriction of focus further delimits the theory:

"The core variable becomes the guide to further data collection and theoretical sampling. The analyst looks for the conditions and consequences and so forth that relate to the core process" (Glaser, 1978, p. 61).

The researcher, through the continued use of the method, eventually has "coded data, a series of memos, and a theory" (Glaser and Strauss, 1967, p. 113).

Summary

Grounded theory is developed through the use of theoretical sampling and the constant comparative method of analysis. The initial interest or sense of wonder about a situation is developed from a very broad view which is enhanced through the application of open coding. The categories and properties that emerge from the data are further explored until ongoing analysis and data collection lead to the discovery of a core category. At this point selective coding takes over from open coding and the theory is further clarified by reduction and theoretical saturation. The theory that results is grounded thoroughly in the data; the process and course of its development ensures that it “fits” and authentically represents the substantive aspect that forms the focus of study.

Glaser(1978, p.62-63) represents grounded theory development as illustrated below in diagram 24. In this way he emphasises that grounded theory is a concept indicator model and the conceptual coding arises from the empirical data. The constant comparative analysis process that is central to the method dictates that indicator is compared with indicator to generate a conceptual code.

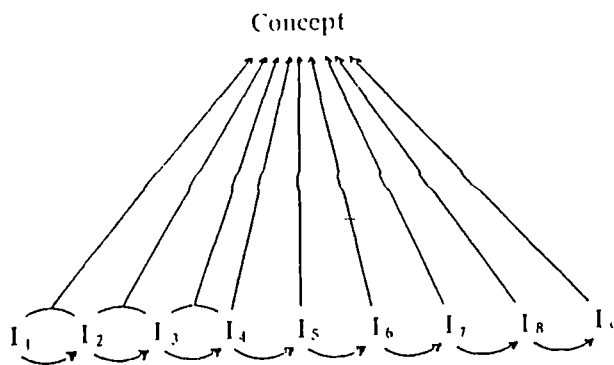


Diagram 24: Grounded theory as a concept indicator model.

Source:Glaser (1978) p.62.

It is through the ongoing application of the method that categories and their dimensions are build up. Each concept and dimension that forms part of

the resultant theory has “earned its way into the theory by systematic generation from the data” (p. 64).

The problems of grounded theory

a) The problem of bias

Glaser(1978, p. 39) addresses the issue of the biases that quite simply enter the study with the researcher. He points out that the background of the researcher sensitises that person to examine certain “broad areas”. It functions, if one is true to grounded theory methods, at the outset, when the area of study is selected; it does not overpower the whole analytical process. Glaser states firmly that: “...the formulation of definitive concepts occurs *after* the researcher has taken the data through analytic phases of conceptualization” and that the:

“sensitizing nature (of one’s theoretical biases and proclivities) lacks specification of attributes, but forms guidelines and reference points which the researcher uses to deductively formulate questions which may then elicit data that leads to inductive concepts being formulated later” (p. 38).

As previously noted, however, Strauss and Corbin (1994, p. 276) accept that the researcher is indeed influenced by intellectual trends and these do affect the analysis. Charmaz (1990, p.1165) discusses the important distinction between having a sound grounding in one’s discipline and being “wedded” to concepts from it so that one cannot see beyond them or “use them in new ways”. Using grounded theory method, she asserts, involves “rendering the actual research data” as well as “developing, refining, revising and transcending concepts within the discipline.” The analysis however, is built on the interpretation of the researcher “of processes within those data” and therefore bias cannot be excluded.

There are two possible solutions to this problem. One is that from the outset those who read or use the research should be aware of the orientation of the researcher in order to alert them to possible sources of bias. Secondly, the researcher could clarify how the data were handled. This point leads to the interesting debate that is occurring between the two originators of the grounded theory method. Strauss and Corbin(1990, chapter 6) for example, indicate that

having found categories in an interview, one could continue to code each interview in order to develop them. But, as "...this could be a long tedious process" (p. 78), they suggest leaving the data and reflecting instead upon the categories in order to generate possible questions. They propose that the use of one's background, the literature and professional experience in this process will increase theoretical sensitivity to the data in subsequent interviews:

"All the answers to the questions raised may not be in the actual data that are before you, but there is no need for concern on that account. It is up to you to take the questions to the next interview and analytic sessions to look for answers" (Strauss and Corbin, 1990, p.80).

If answers are not found in the data the researcher is exhorted to continue searching for them. One must contrast this approach with that of Glaser who sees this as a clear cut case of forcing the data as opposed to trusting to emergence. The data must be allowed to yield the concepts and categories. The constant comparative analysis process ensures that the emerging theory fits the data. Relevant questions will emerge naturally from the data. The approach of Strauss and Corbin (1990) allows one's background to direct the research rather than the emerging theory grounded in the data. As Glaser states, the approach suggested by Strauss and Corbin:

"...is all forced conjecture because surely the data has systematically been ignored in the service of selective use of bits and pieces of the analyst's professional and personal interest" (Glaser, 1992, p. 54).

Therefore, the researcher using grounded theory method at this time needs to state clearly how her theory was developed from the data and how her professional background and the literature relevant to the substantive area affected subsequent analysis.

Application of the grounded theory method to the study

a) Background of the researcher

The professional background of the researcher is in nursing. During recent years, after a period of time working as a Health Visitor, I taught

community nursing topics in a general nursing program(pre Project 2000). During this period I was impressed by the number of patients with leg ulcers that the students discussed on returning from clinical placements in the community. Whereas I had worked in Canada in a District Nursing type post with the Victorian Order of Nurses for Canada, and had cared for an occasional patient with a leg ulcer, the numbers of patients with the condition being discussed by the student nurses seemed inordinately great. This stimulated an initial literature search and the results led to this study. Glaser, (1992, p. 31-32) states that: "There is a need not to review any of the literature in the substantive area under study." As a lecturer in nursing with a remit to teach students during their community placements it would have been professionally inexcusable not to examine the literature of the area. Glaser's rationale for his dictum is that study of the available literature might contaminate or inhibit the researcher's ability to generate categories. However, the nature of the literature is such that contamination was not possible; the few surveys describing the incidence of the problem, its duration and recurrence and its medical treatment were external to the substantive area of interest. The literature divulged a wealth of information about wound care products, about dressings and cleansing agents, but disclosed virtually nothing about the personal experience of the clients nor of the professional management of the condition by nurses. An occasional text included detailed guidelines for the physician (Browse, Burnand and Thomas,1988, for example) but the insight into the professional management by doctors was, again lacking. The initial literature review and my professional background increased my sensitivity to the area; they could not be said in any way to have led the research process.

b) Focus of the study

The research began with an area of interest; there were no "problems" to solve. The research focus was to explore the experiences of the people who have venous ulcers and of those who care professionally for them in order to determine their main concerns and elucidate the core process that resolved them. The area was limited to "venous ulcers" because the variety of leg ulcers is considerable and this type is both the most common and also a manifestation

of an essentially chronic condition. Certain other types of ulcers are associated with cancer, infection, metabolic or arterial disease and their trajectories, from the literature, are clearly very different.

c) Early exploratory work

During this period, a community nursing manager asked for assistance with the newly formed "Leg Ulcer Interest Group". The group consisted of twelve interested District Nurses and they represented the local community teams. The group chose to explore the prevalence of the pathology in the local health district and to gather the views of fellow District Nurses on the diagnosis and management of the condition. I was associated with this group as a resource person and was able to gather information as a participant and as an observer. At this point my data collection began in earnest and the first coding was done.

The group members prepared a questionnaire and distributed it among their colleagues. Given the interest and enthusiasm of the group and their affiliation with every District Nursing base in the locality it was not surprising that the response rate was 92% and included all full time District Nurses and many of the regular part-time staff. Having volunteered to process the responses to the questionnaires I had direct access to that data from thirty one nurses and used it in ongoing open coding. The coding produced a number of possible conceptual leads and what was required now was a fuller exploration. I needed access to District Nurses outside this group and to patients if a fuller exploration of the phenomenon were to be possible.

d)The ethics committee

The next step, that of obtaining access to a wider range of nurses and clients, necessitated formal approval by the Ethics Committee of the Health Authority. The panel of doctors, being unused to qualitative research focused most strenuously on determining whether I intended to interfere with prescribed treatment. Being reassured that this worry was unfounded, they approved the study and their decision gave me approval in principle to approach all patients with the condition and all health professionals who cared for them within the

health authority boundaries. The consultant dermatologist from the hospital was present at that particular meeting of the committee as she had a proposal for approval as well. She expressed considerable interest in my study and invited me to attend her weekly "Leg Ulcer Clinic" where I could have ready access to all her patients and to her staff. This began a very fruitful relationship and her support opened many doors to me for which I shall always be very grateful.

e) Ongoing data collection:

i) The doctors in the community setting

Having received the permission of the Ethics Committee to pursue my inquiry within the Health Authority, I still had to gain access to individual patients with venous ulcers and to health personnel who cared for them. Over a period of two months I made appointments with fourteen General Practitioners who were principals in their practices in the area and through discussion of my proposal with them I was able to gain access to their patients and to their nursing staff. In the course of requesting this access, which was granted in every case, I was able to discuss their views of the care of their patients and to gain their personal and professional opinions; this information was coded and formed the basis of an ongoing conceptual lead that made me pursue the invitation from the consultant dermatologist to attend her clinics. It appeared from the data gathered at this time that doctors were not diagnosing ulcer type and I wanted to compare this with the approach at the consultant clinic. Having started by looking at District Nurses the scope had now expanded to include other health professionals caring for this group of patients.

ii) The nurses and the patients

I approached the District and Practice Nurses associated with each surgery and asked them for lists of their patients with venous ulcers and also for the opportunity to interview each of them in depth at a convenient date and time. Because of this dual request I was later able to associate patient interviews with specific nurses and nursing interviews which proved interesting

and helpful. At the time, however, it must be admitted that it was a happy accident that led to many theoretical memos being written.

All the nurses were happy to provide lists of their patients with “active” venous ulcers and each prepared the way for me by asking if the patients would mind talking to a nurse who was interested in patients with their type of leg ulcers. From the outset I made the decision to include patients in this study who were categorised as “venous” by the nurses or the doctors: no attempt was made to verify the diagnosis being used. In making this decision I knew that by default, some of the patients studied would probably have “mixed” arterial and venous ulcers, or possibly ulcers that were not venous at all. However, the probability was that the majority would be venous in nature and when coding led me to question the inclusion of a patient in the “venous” category, that data could be held until it was verified by other patients’ experiences, or clarification of its exceptional nature was ascertained; all categories earned their way into the theory.

All twenty-eight patients, I was told, were happy to participate and I was given lists of names and addresses. Most patients were interviewed in their homes; a few were seen at the surgery where a room was made available to me on the days the patients attended to have their ulcer dressings changed. Prior to the interviews each patient was given a description of the general nature of my study, was assured of confidentiality and anonymity in any material published or presented as a result of the work. They were reassured that they were perfectly free to participate or to decline the request now or at any point in the future and that their decision would have no bearing on the treatment they were receiving. They knew that I was a “nurse tutor” and separate from the nurses and doctors who cared for them. In the end only one gentleman of 87 years of age declined to participate. He remarked: “I ain’t got time for an interview or such like; at my age breathing is about all I can manage!” All the initial interviews were tape recorded and transcribed verbatim for the purposes of coding and ease of discussion in the interview situation.

The eighteen nurses were interviewed in their places of work and again each interview was tape recorded and transcribed verbatim until the point of selective coding. The nurses needed far more reassurance than their patients

because their initial reaction was concern that their particular clinical practices were being measured or examined. Once the nature of the interview was discussed and anonymity assured, most relaxed and were quite forthcoming in terms of their practices and their views on the subject. The types of nurses in the study was extended from District Nurses to Practice Nurses because in the initial stages of seeking access, the Practice Nurses seemed to be indicating a difference in both the view they held of their patients and also in their approach. Theoretical memoing led to this group being chosen for inclusion and further data collection and analysis.

f) The consultant clinic

Theoretical memos from interviews with the general practitioners and from the nurses and their patients in the community led me to attend the Leg Ulcer Clinic at the hospital. There were differences in approach and treatment that initially appeared to vary with the category of professional controlling treatment and their level of knowledge of the condition. Memoing led me to look for an opportunity to study another group where the control of treatment was different from those already examined and where higher level skills in diagnosis of the condition and treatment options might be the norm: the dermatology department was an obvious choice.

I attended the Leg Ulcer Clinic weekly for a number of months. Attendance gave me the opportunity to meet a number of the staff and the patients, some of whom I had previously met in the community. Eleven patients who had not previously been interviewed were approached at this time and all accepted the invitation. Over time I came to know some of them quite well and they were happy to discuss their treatments, their conditions and their lives in general. Similarly the five nurses became quite relaxed with me over time. Initially they viewed me as “someone from the school” and reacted in a rather anxious manner in my presence. However, I asked them to assist me in regaining some practical nursing skills in their clinic and when they became my teachers and had more opportunity to take my presence for granted, they appeared to respond more normally, inviting me along to coffee and discussing their own lives at break times as one would expect of a ward group.

The nursing staff of the clinic, in contrast with the community, were of mixed grades and it was not unusual to find the State Enrolled Nurses carrying out the majority of the dressings and dealing with the patients most frequently. The Sisters also took their turn in the clinic and over time I had the opportunity to see and hear them all "in action". The two registrars and the consultant could be observed and their practices and interactions noted.

Throughout this time I was also engaged in interviews in the community. As a result of the various groups compared, a comprehensive picture of the substantive area became clear. Selective coding began once the core process of *navigating* emerged. The process of movement from *solo navigating* to *navigating by network* and on to *navigating by pilot* and the two conditions of: *symptom specific* and *condition specific* navigating were elaborated.

g) Ongoing development of the data

As the research progressed I became more and more involved in lecturing on wound care and on the management of patients with leg ulceration in particular. Being invited to speak at major study days I had the opportunity to explore, question, confirm and reformulate previous analytical coding with approximately eight hundred nurses of varying backgrounds. The total number could be asked for confirmation of such aspects of care as: who controls treatment decisions and the frequency with which they had referrals from a doctor with a condition specific diagnosis, that is, a diagnostic label beyond the very superficial one of "leg ulcer". Each of these study days gave me opportunities to discuss issues in more depth with participants at coffee breaks and lunch times and numerous memos were written as a result. Similarly, when asked to teach classes on "Doppler skills" to five nurses from the dermatology department of another consultant clinic, and later to ten Practice Nurses and District Nurses from a neighbouring health district, I was able to continue selective data collection and by this point confirm the theoretical framework that had developed. Ongoing invitations from seven nurses to see patients with venous ulcers in their homes, nursing homes or in hospital, usually with the purpose of determining a Doppler index, gave further opportunities to develop and to validate the theory.

Handling the data

The data were collected from a variety of groups as has already been indicated. What became clear reasonably early on in the process of data collection and analysis was that the groups were by no means “tidy”; a patient cared for by a District Nurse in the community at the time of interview would most likely have been cared for initially by the Practice Nurse and might also attend or have attended the consultant clinic. It was not uncommon to find patients who, in addition, had been cared for during hospitalisation because of their venous ulcers or during treatment of other conditions. This fact however, allowed for a more thorough exploration of the differences the patients perceived in approach and in their treatment: they were the constant in a changing world of health care professionals.

Interviews

Initial interviews with eighteen nurses and twenty-seven patients were tape recorded and transcribed verbatim. This approach was particularly beneficial in the early stages in order to allow me to check the accuracy of my memory and memos of the conversations and also to alert me to aspects I had not “heard” during the interviews and had therefore not sought elaboration for at the time. Initial coding was made immeasurably easier because of the transcriptions. Later interviews were subject to contemporaneous note taking or coding and memoing as soon after the interviews as possible.

Open coding

“Coding, the initial phase of the analytic method, is simply the process of categorizing and sorting data. Codes then serve as shorthand devices to label, separate, compile, and organize data. Codes range from simple, concrete, and topical categories to more general, abstract conceptual categories for an emerging theory” (Charmaz, 1994, p. 97).

In the initial stages the researcher looks for leads in the data and asks what the data is about. Charmaz suggests looking at the data and coding in a number of ways to maximise the yield of codes. She suggests that one first

analyse the context, then look for what is missing, that is, for what the participants “gloss over, or ignore” (p.100). Thirdly, she suggests looking for in vivo codes, that is for descriptors that come directly from the data and finally for processes occurring in the data. Some examples from the study will be presented to illustrate open coding.

Interview statement:

“By gum! Well this one hurts terrible! It’s like a throbbing all the time: grip, grip, grip. Then you drop off to sleep, then all of a sudden its right at the top of the leg to the bottom, and right down there and at the back--it’s that sore--it’s the full leg--it affects it all. They give me eight weeks this time because they said it was improving that much. And the nurses are real pleased with themselves...but I said the soreness is there, it’s terribly sore, it’s sore up there and around the back of the leg. I keep asking if there are any more around the back of the leg. And they say :‘no’. They examine it and say ‘no’.”

Open Codes: personal distress: pain, professional disregard, disruption of normal life: sleep, experiential symptom focus versus “professional symptom” focus

Example 2

Interview statement:

“The older they are, the worse they are in terms of fiddling. They have to have a look, they have to change it: ‘Well, it was leaking’ ‘Well I told you if it leaks to just put another pad on!’ ‘Oh, did you?’

Codes: negative attitude to elderly, expectation of compliance, verbal abuse, unexplored decision making/assumptions(?professional disregard?)

In vivo code: “the older they are, the worse they are”

All the interviews, both formal and informal were dealt with in this way. Statements were analysed and explored for their meaning by asking of each the neutral questions suggested by Glaser.

Focused or selective coding

Focused coding is the second phase of the coding process in which the researcher “takes a limited set of codes that were developed in the initial phase and applies them to large amounts of data...The purpose of focused coding is to build and clarify a category by examining all the data it covers and variations from it” (Charmaz, 1994, p. 102-103). The category initially labelled as “personal disruption: pain” recurred throughout the interviews with the patients and in fact it was the unusual patient who did not recall a period of intense and intrusive pain. The pervasive nature of this category led it to be selected for fuller development. Likewise, the nurses and doctors, on the whole, missed the information they were being given by the patients and this category became known as “professional deafness” in the study. This aspect led the researcher into the literature on pain and on the nursing and medical management of it and this data fed into the development of the code. In this way it can be seen how the developing theory drives the data collection; the literature is entered when indicated by the emerging theory rather than being the driving agent of categorisation and data collection. Interestingly, the pattern of pain described by the patients was not recorded anywhere in the literature and this highlights the professional importance of this issue which was explored in considerable depth.

Similarly the patients indicated an extremely limited knowledge of their condition despite having had it, in some cases for many years; the cause was unknown to them. However, they could all relate specific instructions that had been given to them in order to improve their condition. This aspect was selected for further development because of its pivotal importance in other aspects of management; few patients took an active part in their treatment decisions and few had knowledge with which to do so. Exploration of this issue led to the finding that nurses believe that their patients do not generally want health education and in fact teach their patients about venous ulcers only under certain conditions: “if they ask”, “if it will help to get them healed” and “if they can understand.” As Charmaz states: “Focused coding helps the researcher to outline a framework that preserves the complexities of everyday

life. By showing relationships between categories in ways that explain the issues and events studied, focused coding helps to provide the groundwork for developing explanations and predictions” (p. 104).

Memo writing

Memo writing is an ongoing process throughout a study which uses grounded theory method.

“Memos represent the development of codes from which they are derived...the memo tells what the code is about; it raises the code to a category to be treated analytically” (Charmaz, 1994, p. 106-107).

Glaser (1978, p. 85-86) states that one of their uses is to allow the researcher to explore the data “with nothing crucial at stake”:

“Memos should be run ‘open’ with no claim to fit and integrate into a theory, beyond its immediate grounding, since later, future sortings will finalize fit, work and relevance by the integration of memos into a substantive theory.”

Example: early memo: “Pain: they aren’t listening”

“Why are the nurses consistently failing to see and hear the pain talk of patients? The patients focus is experiential: descriptions of pain are very graphic and deal with the nature, location, duration, --emphatic! When they present these to the nurses the general response is disregard: “You don’t want to get hooked on tablets now, do you?” “Of course it hurts, but as it heals it will settle down.” What is blocking their attention to this very relevant and clearly expressed need from the patients?

Later memo: Professional deafness

“Professional deafness occurs in conditions when the health professional lacks the knowledge or skills required to give professionally competent care to a patient. In situations of professional deafness the professional focus is on the pathology. Professional deafness is the opposite of “supportive assistance”

because the focus of the health professional is diametrically opposed to that of the patient and it is the professional's goals that are at the forefront, not the patient's.

The patients' focus is intimate, personal, experiential; the nurse or doctor dealing with these patients who doesn't know how to diagnose them or, in the case of the nurse, who doesn't have a clearly established medical diagnosis, feels forced to focus on the pathology because the price of mistakes for her and for the patient are so high. Monitoring the response of the wound to treatment gives the prime indicators required in this situation—not the subjective experiences. Secondly, the literature suggests quite strongly that it is no one's job to deal with pain—it is everyone's job to ensure patient safety and this is precisely what they are doing: overlooking the personal to provide physical safety overall.

It is through the writing and sorting of memos that direction is found for ongoing theoretical sampling and the theory is built up. Writing memos forces the researcher to move from the descriptive level to the analytical and to remain there. Sorting allows the researcher to discover the core variable(s) and theoretical sampling and selective coding then lead to saturation and reduction.

Summary

Throughout the research process the researcher has adhered to the principles of grounded theory method as developed by Glaser and Strauss, (1967) and to the techniques elucidated by Glaser(1978, 1992) Where there might have been differences in the development of the theory by following either Strauss and Corbin(1990) or the techniques of Glaser, Glaser has been followed to ensure that the analysis is truly grounded in the data and in no way forced.

In the following section the findings will be presented and discussed. Grounded theory does not rely on numbers but on saturation, however, in order that the reader will have confidence in the data collection for this study a brief summary of sources will be given here.

12 District Nurses in the Leg Ulcer Interest Group
31 District Nurses in the survey organised by the Leg Ulcer Interest Group
14 General Practitioners
1 consultant dermatologist
2 registrars in dermatology
27 patients in the community
23 patients in the dermatology clinics of two hospitals
1 patient in a community hospital
10 consultant clinic nurses in two hospitals
20 District Nurses and
13 Practice Nurses

Chapter 5 Presentation and analysis of the findings

Section A Introduction: shaping the illness experience

All trajectory management is aimed at shaping, that is, at controlling the impact of the illness experience on an individual. Shaping can be achieved by a variety of means: by the structure of a health care organisation or through the processes of prescribing certain treatments, or imparting health education, for example. Shaping interventions may be positive or negative in outcome. An incompetent practitioner might make a mistake causing harm, a patient might react unexpectedly to a prescribed drug or make incorrect decisions based upon incomplete or inaccurate information. On the other hand, a practitioner who has expert knowledge or enhanced interpersonal skills might be able to shape downward trajectories in an upward direction. Many people affect the shape of an individual's health trajectory from those who make decisions about the pollutants in his atmosphere to the individual himself who might decide to lose weight, take up smoking or engage in a cardiac fitness programme.

When faced with a health problem the person's normal health trajectory and overall biography may be seriously threatened. Then the efficient management of care rests upon the accurate determination of the nature of the problem and precise trajectory scheme planning. An incorrect diagnosis on the part of the individual or his health professional might lead to unsuitable and even harmful interventions being selected. However, even technically correct interventions might be detrimental if applied without considering the uniqueness of the individual concerned. When trajectories are well defined and relatively predictable, the hardship experienced by the sufferer can be rationally planned and the overall effects minimised within the constraints of the situation (Strauss et. al. 1984, p.65).

Navigating

The core category to emerge from this study is *navigating*. *Navigating* is a method of shaping our experience including our health trajectories. It is a process of captaining, steering, path-finding or charting a course. It is an activity in which we are all engaged as we plan our lives, seek to avoid dangers and select the most advantageous routes to our goals. We routinely navigate in

relation to our health by making decisions about suitable responses to the variety of signs and symptoms that we experience, or to such things as invitations to visit person clinics or screening services. Under normal circumstances we navigate for ourselves: we are in control of our own decision making and choose according to the way we interpret our world. Except in very unusual conditions, navigating is a uniquely personal response and decisions are made in the context of our biographies.

Navigating in relation to health can be done on either of two levels: *symptom specific* or *condition specific*. To illustrate the former, consider the individual who responds to a minor burn by applying lavender oil to a wound by cleaning it and applying a dry dressing or to a headache by taking aspirin tablets. This level of *navigating* is more suitable in general, to acute illness episodes where symptom relief often equates to a restoration of health. In these examples, the individual's life is unexpectedly interrupted for a short period of time and the signs and symptoms can often be managed within the framework of his usual biography. By contrast, *condition specific navigating* relates more to chronic illness management in which the individual needs to appreciate the wider implications of his disease, his personal response to it and the reciprocal impact of the illness and its management on his life. Examples of these situations might include that of a patient with diabetes who must learn to balance diet, activity, and insulin, or the person with asthma who needs to learn to use an inhaler or to limit exposure to trigger agents such as cigarette smoke. In these instances, responding in a symptom specific manner might work in the short term but the individual's life would become a constant round of crisis intervention and normal biographical work would be seriously threatened.

Our safety and success as navigators in terms of our health depends upon our ability to interpret the indicators before us and to select suitable responses. In our efforts to make sense of our present symptoms we mentally process the information available to us in relation to previous health experiences. Even when quite unusual in nature we may attempt to normalise them by such comparisons and to thereby render them as innocuous (Johnson, 1991, p19). The meaning we give to our experiences is very personal in nature and is not readily apparent to others.

A person may, through past learning and experience, be an expert at *navigating* a personal course through a particular illness. The learning may be quite private in nature and the individual might never have consulted a health professional in the pursuit of such mastery. However, in many cases of chronic illness the vagueness of emergent symptoms or their escalating nature might cause the individual to consult. In order to move from *symptom specific* to *condition specific navigating*, the individual has to obtain a medical diagnosis. With the determination of his underlying problem he becomes able to navigate from a more theoretical perspective being aware of the illness in general as well as his response to it in particular. The knowledge of the underlying condition provides him with a navigational chart as it were.

When the nature of a health condition is determined to be a chronic one, control of navigation is routinely handed back to the individual carefully and purposefully because it is not appropriate, safe, nor practicable for a professional to have control of an individual's life long illness management. The patient may be taught additional skills or given more knowledge in order to fit him for ongoing *navigating*. Only when he has control of navigating will he be able to incorporate the demands of the illness and its management into his biography so that, for the most part, it becomes a consideration but not the salient feature of his life.

Professional piloting

In the experience of an acute or chronic illness it is appropriate and sometimes life saving to have a professional act as an occasional "pilot" but the management of the day to day health and illness trajectory has to rest with the patient. The process of piloting is a specific shaping process that aims to provide "supportive assistance", as described in the Corbin and Strauss trajectory model (Corbin and Strauss, 1992, p.21). Piloting is the appropriate activity of the expert or health professional who may take temporary control of certain aspects of an individual's life in order to guide him through a difficult or dangerous period. What differentiates a pilot from a navigator is that the former is an expert who has a very specialised function that is appropriate usually for a short duration. The navigator, by contrast has a sound general knowledge of

the suitability of specific interventions as they will effect him as an individual; the two functions are complementary. When individuals become acutely ill or experience unusual symptoms in their chronic illness trajectories the professional pilot is the expert who might be consulted in order to gain safe passage in dangerous or unusual circumstances. The goal of the professional pilot is always to enable the navigator to assume his normal role as quickly and completely as possible.

Navigating and piloting in venous ulceration

Venous hypertension complicated by an ulcer is a condition that must be navigated at the condition specific level in order to minimise the impact on the life of the patient. This means that the patient must have the knowledge and skills required to manage this own trajectory. If an individual or a health professional were to treat a venous ulcer as if it were merely a wound, that is, at the symptom specific level, healing would most likely be delayed, at best, or, complicated by progressive deterioration.

A person who develops a venous ulcer goes through the process of believing that his wound is indeed just that: a simple skin lesion that will heal as all others before it have done. When the signs and symptoms escalate to the level of interfering with the person's normal life, he seeks the assistance of a pilot in health matters: the general practitioner. He hands control over to the doctor as might be appropriate in acute care and this is an important point to note in order to understand all that follows. As Charmaz(1991, p.15-16) emphasises, the individual does not see a chronic disorder at the initial point of consultation but rather views his signs and symptoms as a mere "interruption" in the course of normal health; viewing the situation in this way he assumes the sick role which supports: "...the active physician and a relatively passive patient" as well as the idea that compliance will result in cure.

However, a cure is not even attempted in the case of the patient with a venous ulcer. The doctor prescribes symptom specific treatment which he anticipates will result in piloting him through the worst of his symptoms and then refers him to the nurse for ongoing care without first determining the condition specific diagnosis. The net result of this anomalous arrangement is

that the patient's period of personal navigating is followed by a brief period of medical piloting, only to be followed by a prolonged period of nurse navigating.

When the doctor treats the chronic condition, which the venous ulcer most often represents, as if it were merely an acute problem signified by pain or infection and refers the patient for ongoing wound management to the nurse, the patient may become locked into a "chronic sidetrack" (Roth 1963, p.106). The patient without the requisite level of diagnosis, appears in this circumstance to be receiving adequate care but in fact he is being managed inappropriately and in a way unlikely to result in his recovery even within the constraints imposed by a chronic illness. The nurse who receives the referral from the doctor with the general, symptom specific label of "leg ulcer" or "wound", has the remit of dealing with his wound care and this is *within her* sphere of competence. Wound care, as rightly practised by a nurse is a piloting function: the surgical dressing, the first aid bandage, or the dressing applied to a bedsore or a fungating wound. Each of these examples is prefaced by a clear diagnosis at the appropriate level.

However, when the nurse begins to deal with a patient's "leg ulcer" she takes on a navigating role because of the unusual nature of this situation. The nurse realises from the outset that the wound is a chronic one and she knows that a condition specific diagnosis must be made if the patient is to be competently managed. Therefore all her attention is initially focused upon the wound and the story of the patient is used to assist her in determining the medical diagnosis of ulcer type. That this type of diagnosis is not within her domain is not as obvious as it might appear. Consider the total situation: a) the patient has been referred to her by the doctor for management, b) it is custom and practice for nurses to accept the management of wound care, and c) the nurses within her professional grouping as District or Practice Nurses accept this role as a normative expectation.

The nurse knows that she cannot act as a pilot because if she were to do so the patient's wound would probably deteriorate. As it is a chronic wound the underlying pathology needs to be determined. In order to approach the required diagnostic certainty she must care for the patient over time and gauge his response her treatment. Because the doctor has failed to make the medical

diagnosis, the nurse takes on this function and in so doing becomes the navigator of the as yet unknown trajectory.

If the doctor were to fulfill his role and determine the medical diagnosis at the condition specific level, then the nurse could be correctly deployed in guiding the patient through the acute or crisis phase that led him to consult the doctor by, for example, teaching him how to care for his wound and prevent infection, how to decrease oedema. and how to normalise his life. When other chronic conditions are considered, such as diabetes or asthma, the nurse's role is that of a pilot who helps the patient in very specific ways to deal with specialised needs. She may teach him how to use equipment such as syringes or inhalers, teach him about his condition and how it can be managed within as normal a life as possible. When she knows the underlying nature of the problem she can concentrate on helping that particular patient to adjust to the limitations imposed by the illness and its treatment. When, in the case of the patient with a "leg ulcer", she does not have this information, she focuses on the pathology and an awareness of the individual's other needs comes, if ever, much later in their relationship. The medical colleague who would not contemplate referring a patient to her for the diagnosis of symptoms such as a "wheeze" or a "headache" does just that when he sends the patients through with the label of "leg ulcer" or "chronic wound."

The medical practitioner has a very specific task to perform in relation to all his patients: he must determine the nature of their problems and the level of diagnosis required to guide treatment. When he pilots their course incorrectly the effects can be devastating. Stewart and Sullivan (1982, page 1399-1401) illustrate this point in their discussion of the problems faced by patients with, as yet undiagnosed, multiple sclerosis. The ill defined constellation of symptoms in these patients is easily labelled as neurotic or psychosomatic behaviour and treated as such. The consequences for the patient are far reaching: when the patient fails to receive an accurate medical diagnosis at the *condition specific* level, he is treated inappropriately by both his doctor and perhaps by his family and friends who come to believe, with the doctor, that nothing is really the matter. At least for these patients accurate diagnosis is usually obtained, albeit after a number of years; the patient with a leg ulcer rarely obtains such

accuracy by professional intervention but is eventually labelled by default due to his response to *symptom specific* treatments over periods of months or years. Like the patients with multiple sclerosis described by Stewart and Sullivan, the patients with leg ulcers move through the “nonserious” and “serious” phases when they assess the importance of their situation and symptoms. However, instead of moving on next to what they term the “diagnosis phase”, those with leg ulcers skip this phase entirely and move on to a treatment phase. The omission of the “diagnosis phase” is very important because it is the crucial oversight that allows the precarious and unprofessional treatment that follows to be seen as acceptable: it leads to *professional navigating* in chronic illness.

Summary

There are times when the doctor can legitimately use a *symptom specific* diagnosis and the treatment the patient receives is in no way compromised. The patient with “hypertension” for example, is treated according to his main presenting symptom; it is not useful to attempt to determine the underlying pathology for the vast majority of patients with this symptom. Similarly a patient with a “chest infection” or a “wound infection” can usually be effectively treated without the precise nature of the condition being determined. In these cases superficial labelling at the *sign and symptom specific level* is all that is required and in fact further exploration would be both costly and time consuming for all concerned. Herein lies the key element: the art and science of medicine rest on the diagnostic acumen of the practitioner and his ability correctly to differentiate those situations in which the *symptom specific* labels of, say, headache, cystitis, and backache are appropriate and when further exploration would yield the *condition specific* labels of astrocytoma, diabetes, and osteoporosis. In the case of the patient with the signs and symptoms of a “leg ulcer”, adequate and safe treatment depend upon the determination of the *condition specific diagnosis* being made and yet this accuracy and level are rarely even attempted.

The situation one would expect in health and illness in general is illustrated in Table 6. The processes of *navigating* and *piloting* are placed in the context of acute or chronic illness and the appropriate roles of the

individual and the health professional are shown. As can be seen, the individual is the rightful navigator in acute illness that is able to be contained within his biography with relative ease, but he may defer to a professional pilot for symptom control. The professional pilot in these circumstances must determine the level of diagnosis required and respond by treatment of the symptoms alone, or, in addition, by further diagnostic work to define the condition. In the case of chronic illness, the individual is the rightful navigator and the function of the health professional remains that of a pilot who is available as an expert when required to deal with acute phases of the trajectory or to make the required course corrections in medical/nursing treatment.

	ACUTE ILLNESS	CHRONIC ILLNESS
LAY SHAPING PROCESS: NAVIGATING	GOAL: <i>SYMPTOM SPECIFIC</i> SHAPING TO DEAL WITH A SHORT INTERRUPTION TO ONE'S NORMAL BIOGRAPHY	GOAL: <i>CONDITION</i> <i>SPECIFIC</i> SHAPING TO NORMALISE ONE'S LIFE BY INCORPORATING THE CHRONIC ILLNESS AND ITS MANAGEMENT INTO ONE'S BIOGRAPHY
PROFESSIONAL SHAPING PROCESS: PILOTING	GOAL: <i>SYMPTOM</i> SPECIFIC SHAPING OR <i>CONDITION SPECIFIC</i> DIAGNOSIS . PRESCRIPTION AIMED AT RECOVERY OR AT RETURN TO PERSONAL <i>NAVIGATING</i>	GOAL: CONTROL OF AN UNRESOLVED PROBLEM OR AN ACUTE/CRISIS SITUATION IN THE CHRONIC TRAJECTORY FOR THE PURPOSE OF MAKING A PROFESSIONALLY REQUIRED COURSE CORRECTION BEFORE RETURN TO PERSONAL <i>NAVIGATING</i>

Table 6 Lay Navigating and Professional Piloting in Acute and Chronic Illness

Section B Personal navigating in venous ulceration

For people who develop a venous ulcer there comes a point, as has been indicated, when the decision is made to seek formal medical help. Although the onset of the signs and symptoms of venous hypertension often begins years before the formation of an ulcer, it is unusual for the person to consult a health professional in the prodromal period. There is indeed considerable time for secondary prevention, that is, for interventions aimed at health maintenance and at limiting the progression of the disorder. However, this time is routinely lost because neither the professionals nor the individuals experiencing the signs and symptoms recognise them as indicative of the progress of venous hypertension. In fact, there is such a lack of knowledge about the condition even among the doctors and nurses who treat it routinely, that it was not surprising to find that there are no surgeries where screening is offered for wounds and none where an examination of the lower limb is included in other routine encounters such as the well woman and well man clinics. Because the process of the condition is not generally understood, all attention and resources in time and money are devoted towards dealing with the most obvious sign: the ulcer.

Even after the onset of the ulcer, people routinely take months to come forward to health care professionals for advice and treatment. The delay in seeking treatment is associated with the development of more advanced pathology and with increased morbidity and expense. Considerable suffering results from failure to gain access to competent professional help. At an early stage some people might be cured of their underlying problem and recent research has indicated that even at the point of ulceration, early management is associated with shorter healing times(Rijswijk, 1993, Skene et al., 1992). It would seem to be in the person's best interest to seek professional help early but this does not usually occur unless serious trauma has caused the wound and the decision to seek professional help is obviously indicated.

There are a number of points at which the person might be expected to seek help. Situations in which a deviation from the normal experience of the body becomes readily apparent would include: the hardening of the skin associated with the development of lipodermatosclerosis, the occurrence of

haemosiderin pigmentation (the reddish-purple staining of the skin caused by the breakdown of the red blood cells in the superficial tissues), the appearance of varicose veins of an aesthetically or a symptomatically unacceptable nature. In short, consultation might reasonably be anticipated at a number of points prior to the development of an actual ulcer. However, if these precursors are not deemed significant enough to necessitate consultation with a health care professional, then the apparently trivial occurrence of a slight cut or a minor abrasion which marks the entry for many people into the final and most noticeable stage of venous hypertension certainly will not. The passage between the status of self-carer and patient, between well and ill is being negotiated during this period and because there is "an inability or failure to read the signs of passage, ... opportune moments of control are missed" (Glaser and Strauss, 1971, p. 73). These missed opportunities have serious implications for the patient and for the professionals concerned and will be discussed in detail in this chapter.

Personal navigating: making decisions in self care

When a person experiences signs or symptoms of illness, unless they are of an overwhelming nature, he will tend to undertake a period of self care which might include self treatment. "Self-care in its various forms, preventive, curative and rehabilitative...is the basic health behaviour in all societies past and present" (Dean, 1981, p. 673). Although professionals tend to view self-care and care provided by others as inferior to their own, it is in fact professional care that is the supplemental form (Dean, 1986, p. 275). As a concept, self-care has many meanings that vary with the orientation of the user. Here it refers to responses to illness and is defined as:

"the range of individual behaviour involved in symptom recognition and evaluation, and in decisions regarding symptom responses, including decisions to do nothing about symptoms, to treat the symptoms by self-determined actions or to seek advice regarding treatment. Self-care thus includes consultation in the lay, professional and alternative care networks as well as evaluation of and decisions regarding action based on the advice obtained in consultation"(Dean 1986, p. 276).

It is that part of care that may be influenced by others but which is controlled or organised by the individual.

The pre-consultation decisions and actions of people with venous hypertension have not been previously studied. Although it is a normative expectation that people will seek medical help when they notice a significant alteration in their health, it was noted in this study that a remarkable amount of deviation from the norm was contained within self care. Even after the development of a wound, self care continued for the majority for over six months and for many, for more than a year. To the health professional it seems obvious that the diagnosis on which the individual's trajectory projection was based was inaccurate and yet self treatment continued, inexplicably, well beyond that which would be considered a reasonable period of time. It is important to understand why this situation exists; if health care professionals wish to influence perceptions and alter subsequent actions they must first gain an understanding of the basis of these early decisions.

Venous hypertension is for most people a chronic and incurable disorder. As a chronic health problem it develops slowly and there is considerable time for the sufferer to adapt to the physical changes occurring over time. To diagnose these accumulating signs and symptoms as being part of a larger trajectory of venous hypertension is beyond the scope of most lay people: in truth, only the minority of health professionals would be aware of their significance. This early period is one of "establishing the boundaries of normality" in which the individuals attempt to "control, limit and normalize" their symptoms (Chasse, 1991, p. 90). He or she might note the various effects but without the knowledge to link them into a single trajectory, would not see an escalation in the expression of venous hypertension. The type of decision making required of the person with venous hypertension is not unique and will be shared with other people for whom a chronic condition emerges slowly. The person has a number of problems to resolve: the meaning of any alteration in the normal experience of the body and health, the nature, extent and duration of self and lay care to employ, the point in the experience when a health professional should be consulted. Indeed within the trajectory framework he has much work to do. Faced with a previously unknown trajectory the diagnostic work becomes even more complex.

The stages of personal navigating

Three stages of personal navigating emerge from this study a) *Solo navigating*, b) *Navigating by network* and c) *Navigating by consulting a pilot*. *Solo navigating* is carried out with the individual as the sole care provider. He does not consult with others available to him simply because he sees no need to do so. This phase is typical of the early stages of ulcer formation when the person is sure that he is dealing with a simple wound. *Navigating by network* is a phase that only some individuals enter. It typically begins after weeks of *Solo navigating* and can be subdivided into: *Navigating by guidance* or *Navigating by Direction*. In *Navigating by guidance*, the individual with the nonhealing wound has begun to feel concern that perhaps he is wrong in his personal diagnosis. It is becoming increasingly clear to him that his charted course is inadequate in obtaining healing. His reaction is to seek guidance of someone in his immediate network. He is certain in his own mind that he does not need a professional pilot; all he needs is a second opinion and some advice on which to make a small course correction. In the second situation of *Navigating by direction*, it is the people in the immediate network who crowd in upon the *Solo navigator*. For this situation to emerge, the *Solo navigator* must be a close social contact and those without family or close friends who feel comfortable in this more direct approach do not enter this subphase. It is interesting to note that all who enter the phase of *Navigating by network* do so believing firmly that they do not need a *professional navigator* and even when this opinion is challenged by their advisers, they do not accept it readily. *Navigating by consulting a pilot* comes to each and every one with a nonhealing wound eventually but not easily; each needs a major symptom to develop: either pain, discharge or significant enlargement of the ulcer size.

The prediagnosis phase

Solo Navigating	Familiar signs and symptoms "Known trajectory": wound healing Predictable course, Self care
Navigating by Network: a) Guidance	Members of the network are consulted: friends with same/similar problem or nonmedical health professionals
:b) Direction	Members of the network enter into the situation without invitation due to concern about the well-being of the individual and a sense of certainty that a wrong course has been charted. They exert pressure to relinquish control to a professional pilot
Navigating by Pilot	Escalation of signs and symptoms: pain, oedema, exudate, deterioration, increase in wound size. These force the decision to seek professional pilot.

Table 7 Phases of navigating in the prediagnosis phase

Solo navigating: perceived seriousness of signs and symptoms

A key determinant of action when a person is faced with signs and symptoms is not their type but their perceived seriousness. It is on the basis of this determination that decisions relating to the appropriate course of action are made. As has been stated, the people in this study incorporated a considerable amount of deviation from the norm into their daily lives without recourse to a professional. This finding is not unusual. In their investigation of self-care

behaviours in Denmark, Dean and her colleagues(1986) obtained data on 1462 people randomly selected from the population. They returned a self administered postal questionnaire and in depth interviews were then carried out on a geographic sub sample of 450 in order to gather information about all symptoms that had been experienced within the previous 6 month period. Interestingly, 7 percent of the total number of respondents did nothing about influenza symptoms and 29 percent did nothing about chest pains. If symptoms were not evaluated as being serious, they did not result in the decision to undertake some form of active treatment. The "self-care responses to illness" Dean concludes, "are a synthesis of learning and experience" (Dean, 1986, p. 279).

The research of Haug and her colleagues(1989) confirm these findings and introduce some interesting additional insights relating to the role played by belief in the efficacy of consultation with a doctor. One of the underlying reasons that they focused on the self-care behaviours of older adults was the spiralling health care costs absorbed by this group in America. People over 65 years of age constitute 11 % of the population and absorb 28% of the health care budget. Whereas self care for non serious complaints protects the health service from increased demand, self care practices that cause critical delays in diagnosis and treatment, obviously increase the financial burden unduly. Haug and her colleagues defined self care in terms of "a decision to respond to a perceived symptom" which involved self-diagnosis and the decision to react. The sample consisted of 728 Americans aged 45-94 selected randomly from non-institutionalised people in three communities.

In keeping with other health care research they found that the majority of their sample had experienced some symptoms during the study period. The mean number of symptoms was 5.7. Their hypothesis that the rate of self care would be higher for symptoms perceived as less serious was confirmed(p. 176). As in Dean's study it is interesting to note the type of symptoms that were considered to be of a serious nature: flu like symptoms (diarrhoea, severe sore throat, runny nose) came first, followed by heart pains and headaches.

The finding that the perceived seriousness of the symptom is the critical factor in determining action was also found in the work of Segall and Goldstein

(1989) who studied self care in a Canadian city. They found that responses were symptom specific. Conditions that would most often lead to professional consultation included: loss of weight, shortness of breath and frequent headaches. Conditions most likely to be self treated included stomach upset, bowel irregularity and problems in sleeping. Although, the individual perception of the seriousness of the symptom most strongly influenced the treatment decision, scepticism about the efficacy of medical care led some to self treat (p. 158). Haug et al. (1989, p.178) also noted that the decision to self treat in situations where the symptoms were perceived as serious was linked to the level of faith the individual had in the doctor. In addition the person's level of self reliance and belief that the symptoms were due to ageing and therefore not amenable to treatment also influenced the decisions.

In all three studies, the individual perception of the seriousness of the symptom being experienced was found to be the cue to action. The obvious question then becomes: what factors affect the perception of seriousness? Twaddle(1974, p. 35) in exploring the concept of "health status" concluded that although signs and symptoms might be physical or behavioural they are assessed in the social context; how one views one's deviation from the norm is dependent upon a number of factors: age, culture, role requirements and the opinions of "status definers" such as doctors. "Except in extreme cases, deviations from normality are inherently ambiguous....(and) are events requiring interpretation"(p. 37). A person will be likely to perceive his health situation as serious if his signs and symptoms interfere with an activity considered as important: health status and role requirements are intimately linked.

The signs and symptoms

The signs and symptoms the individuals in this study were interpreting, appear, on the whole, to be very minor indeed. There were two types of symptoms that had to be assessed in the initial period: a) those related to a wound of traumatic origin or, b) those related to what appeared to be spontaneously occurring minor skin changes. In the illustrations given below it

will be readily apparent that it was quite reasonable to expect the skin to heal normally and to view the physical damage as relatively insignificant.

a) Traumatically induced injuries

- “I had an accident at work and slipped in a wagon and caught my leg and it didn’t sort of heal.” However, the damage to the skin looked minor and he continued to care for it himself for six weeks.
- “I never saw it with carrying the cabinet. Well, I caught it--caught me toe in the line and fell in the footings. It was a concrete path, you see, and it was the edge of the concrete that fetched the skin off”. This injury seemed minor and was self treated for twelve months.
- “I used to work on the land a bit and I got what looked like a blister on the side” This lady’s ulcer began with what she thought was an insect bite.
- “Oh, yes, I caught the first one I had on a rusty tea chest.” That lady self treated for weeks.
- “I just knocked my ankle and scuffed the first layer of skin up—that’s all and it went from there.” This person self treated her wound with the common antiseptic agents of Germolene and Savlon. She also applied a house leek “as my mother was a great believer in that sort of thing!”
- “I got into the bath with the water too hot. It caused a blister.” This lady self treated for three weeks. Subsequently, four years later, she dropped the ring of a millers weight on her ankle and another ulcer formed.

b) The skin change group

- “It started off, you know when your hands are chapped? Well, it was all rough like that and that’s how it started--nothing else. I haven’t knocked it or anything, but it was through roughness of the leg, as if it had been chapped you know.” This informant self treated for months with Vaseline to moisturise the skin.
- “It was just like, you know, a spot that wouldn’t go away and kept growing a hard top.”
- “They come like a blister when they start and even a bandage irritates them” said one lady of 85 years of age. This symptom was minor and she treated the irritation with the topical anesthetic cream, Lanocaine.

In all of these cases the injuries, while perhaps initially quite painful, or the changes in the skin, rather unusual, were not sufficiently problematic to prevent the individuals concerned from carrying on with their normal lives. Consultation with a health professional was not even considered at this stage. As has been shown, most of us have symptoms most of the time and we contain them within self care quite adequately. Alonzo(1979) explored the experiences of people who had signs and symptoms of illness that were potentially significant medically and socially but for which the decision was made to self treat. His conceptual approach was based upon the “assumption that the process of illness definition emerges within socially defined situations against the total background of daily life and relations with others” (p. 397). The core category that emerged from his study was “containment”. In discussing this concept he explored the “bodily background expectancies” and considered the situational implications of performance. There are strong links in his article with the “biographical body conceptions” and “reciprocal impact” that Corbin and Strauss develop in their later work (Corbin and Strauss,1992, p. 19). Alonzo found four types of situations in which decision making occurs: Type 1 refers to the normal situations in which anticipated performances or

participation are not expected to produce signs and symptoms. Type 2 situations have the potential to produce signs and symptoms of illness or injury but because this is known and anticipated, containment is possible. An example of this type would be a long flight when a person with a venous ulcer would have to keep his leg in a dependent position for prolonged periods and during which the atmospheric pressure in the plane might be less than normal. If the implications of both pressure and position are understood, then action can be taken to prevent either increased oedema or exudate. In Type 3 situations people have the freedom to accommodate signs and symptoms in their social lives by making them the primary focus of attention for brief periods of time. For example, a person with a leg wound that was increasingly painful might be able to contain the signs and symptoms by taking more time to rest or to change a dressing. Life in type 3 situations is not so structured as to prevent "free time" or "breaks in the action" to deal with the illness experience. In Type 4 situations, "termed diagnostic, illness, health training or therapeutic situations, bodily problems are given dominant situational attention" (p. 400). In these situations a person with a venous ulcer might be hospitalised because of an acute infection or he might take a few days off work to rest his legs and reduce the oedema, for example. Containment is not possible in a Type 4 situation and the goal is to effect the changes required to allow containment within the normal parameters of daily life. Similarities can be seen between these "types" and the "stable", "unstable" and "acute" phases of the Corbin and Strauss trajectory model and the concepts of "trajectory management" and "shaping". Applying Alonzo's findings to this study, it is quite clear that in the beginning stages of ulceration, containment is not only possible, it is predictable. Each eventually reached a "type 4" situation but until then, it was perfectly reasonable for each to continue self care.

However, it is not just the types of situations that determine action. Alonzo discussed eight factors that influence containment: a) level of engrossment, b) the individual's and others assessment of his performance, c) the relative status of the individual compared with the others with him in the situation, d) issues relating to the propriety of containment in certain situations, e) the extent to which resources can be mobilised to alter or contain the signs and

symptoms, f) the ability to avoid situations that would make containment impossible g) the nature of the signs and symptoms themselves and h), the sex of the person involved.

People can be so engrossed with their normal lives that they can ignore signs and symptoms but perhaps only to the extent that those indicators can be relegated to the background of a situation. Alonzo notes that:

"...some situations are so engrossing and so much a part of an individual's identity that he is oblivious to signs and symptoms and/or feels so obligated and committed to a particular situation that continued participation and containment are believed essential and appropriate" (p. 401).

Containment is possible when performance is not affected significantly within the specific situation. This factor may act for the patient with a venous ulcer or for any individual with a chronic illness developing slowly over time. Alonzo noted that the severity of the symptoms experienced was a major consideration in determining whether or not an individual could continue to focus on his normal life and in this study it was found to be the escalation of symptoms and the disruption to normality that led to consultation with a doctor. However, before that happened, each was faced with the problem of decision making in situations marked by uncertainty. They were well aware of their non healing wounds and puzzled that their approaches to wound management were not working.

Uncertainty in illness

Each of the patients in this study had started with what appeared to be minor skin lesions. None anticipated a prolonged period of non healing. The lack of movement towards healing led each into a period of uncertainty. As defined by Mishel (1988) uncertainty is the:

"inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues" (p.225).

Within her theory of uncertainty, Mishel states that patients, to avoid uncertainty, need to develop a "cognitive schema" which is their individual

interpretation of the illness and its treatment. The primary sources of this schema are: the symptom pattern, the event familiarity and event congruence. The symptom pattern viewed by the patient with a wound or ulcer would refer to the extent to which the pathology experienced was consistent with his definition of a wound. The event familiarity would refer to the degree to which this health event fitted into his memories of similar occurrences: if previous wounds of this type healed without complication or further intervention then the person's familiarity with the occurrence would make it appear normal. Up to a point, event congruence could be held by each of the patients with "simple wounds" ; that is, until a period of time has passed or until untoward symptoms developed, the person could continue to believe that the expected was that which was being experienced. However, once the cognitive schema was found to be flawed, uncertainty developed. In this situation, the individual has two aids to resolution of his uncertainty according to Mishel's theory: his cognitive capacity which refers to his information processing abilities, and his structure providers who are usually key people within his network.

Navigating in the lay network

As the situations became defined as increasingly ambiguous and there was increasing concern over the meaning of signs and symptoms one would have expected consultation to occur if there were the appropriate members in the persons social network to permit this. Therefore in the early stages of venous ulceration, for the period of time immediately after minor wounding or lesion appearance, consultation within the lay network would not be anticipated. Consultation would be expected, however, after this initial period. Freidson (1970, p. 290-291) stated that, whereas it may be the individual who is aware that something is wrong with him, it is the group that endorses the privileges afforded to the ill. He further asserted that when the individual feels that he may be ill, he would be likely to seek the advice of those around him to clarify his situation and to gain advice about what he should do about his signs and symptoms. This context of consultation, however, does not apply to the majority of persons who develop a venous ulcer. They are not seeking legitimisation from a social group to occupy a "sick role" or asking to be granted

exemptions from paid labour; the health problems involved, generally, are managed within the context of everyday life. The social group has no specific legitimising function in relation to those with venous ulceration and therefore there is no formal need to consult for that reason. Nevertheless, one might expect the increasing ambiguity and uncertainty to lead the individual to discuss his problem. Interestingly, in this study, the majority reported that they did not consult within their networks.

Continuing solo navigating in uncertainty

The vast majority of people remembered making their key decisions on their own and said that they had not consulted either non-medical health professionals or family and friends, nor had they been given unsolicited advice. Their course began in Solo Navigating and moved directly to Navigating by Pilot when they had made the decision that they required expert help. How accurate are their memories? It would seem to make such strong intuitive sense that people in social settings in conditions of uncertainty would consult others. Elliott-Binns, a general practitioner in Northampton examined "lay medicine" in his practice on two occasions using identical instruments. The first study of 1000 patients in 1970 and the second of 500 patients in 1985 indicated that it was the norm for his patients to have :

"received on average two items of advice before seeing the doctor, the chief sources being friends, spouses and other relatives, with significant contributions from chemists, the media and those with nursing or other professional training " (1986, p. 542).

Those who reported no sources of advice (122 or 12.2% in the initial study) most often had a relevant reason for doing so: being widowed, divorced, having a personality disorder, or living alone, for example(1973, p. 262). The "impersonal sources" of information, such as television and magazines had increased in importance since the 1970 study rising from 16.2% to 23.4% in 1985 but still accounted for only a small part of the lay medicine.

Lay consultation is difficult to study because it relies on memory and the personal importance attributed to conversations. Furstenberg and Davis (1984)considered that people tend to disregard the influence of the conversations they have relating to health matters: "most discounted the

importance of such conversations and rejected the idea of influence by others, general questions about advice or consultation yield mainly denials”(p. 829). They found that “spontaneous voluntary reports are a more valid representation of what actually occurred than are accounts offered in response to direct questions” (p. 836). This view highlights the importance of method; grounded theory has the strength of allowing information to emerge more spontaneously than is allowed in other approaches.

Navigating by guidance

A few individuals with an ulcer did seek help or advice from others in their network. One lady, for example, who knew that a retired teacher in the village was particularly good at herbal remedies asked his advice and acted on his suggestion. She couldn't remember what she had used but said that it had helped “a bit”. Another gentleman mentioned that he had asked a friend what ointment he used on his wounds and as a result he tried the suggested treatment. Those who were in work often had increased chances of seeking guidance due to the larger social networks and contacts. No where else is this better illustrated than in the case of the village shop keeper who is so often at the hub of an entire community:

“The District Nurse came into my shop one day. I knew her quite well. I asked her about it (a leg wound) and she said: ‘Show me your leg’ and she told me to get off up to the doctor’s and make an appointment to see him.”

Those with more limited networks, the housebound for example, gave occasional instances when they sought a second opinion:

“Well, I had a chiropodist—he came once a month—and I said to him: ‘Would you mind looking at the back of my leg?’ And he said: ‘No I don’t mind. What’s the matter with it?’ I said: ‘I don’t know but it’s very, very sore and I don’t know what to do about it.’ And he said: ‘I’ll tell you what to do about that leg: go to the doctor’s!’”

“I’ve nearly forgot what happened, but it was this leg at the back. There was a little nasty place nearly as big as your thumbnail. I asked the doctor to call for some reason—I don’t think it was for that though, but I showed it to him and he said it was all right what I was putting on it.”

Notice in this last illustration that a medical consultation actually took place. The response confirmed the lady in her lay navigating approach to wound management. It was an unplanned, opportunistic encounter but perhaps it was remembered because of the relative status of the person consulted.

There may indeed be more consulting than the individuals concerned remember and it may be such an everyday and casual activity to discuss health matters that it does not stand out as a distinct memory. However, perhaps ready access to one's doctor and faith in him precluded the need to network in the lay system and this was one of the conclusions of the study of lay consultation carried out by Furstenberg and Davis (1984). They explored the issues with a small sample of self-selecting older people (N=12 Jewish people, eight women and 4 men, aged 66-97, seven of whom were widowed, one was single and four were living with their partners). They assumed that as older people tend to suffer from one or more chronic diseases they would have more opportunities within their social contacts to gain information from others who shared their health problem. "Expert" lay knowledge should abound. However, they also acknowledged that age brings a decrease in social networks due to retirement, deaths, and decreasing mobility. They gathered information by means of structured and focused interviews and a health log. They found four types of conversations concerning health problems: a) "consulting" in which the specific intention was to gain information, b) "reporting", which was essentially information sharing within a close social network of family and friends, c) "instrumental" which was used in situations where one was dependent on others for some kinds of help or where others were a means of gaining that help, and d) "non-reporting" where discussion of health was avoided. In consulting conversations the persons consulted were chosen because they would either know about the health problem from their previous occupations or would be able to advise because they suffered from it:

"Conversation partners who had first hand experience, past or present, with the condition, became a source of special types of

information. They had direct knowledge of the remedies and the practitioners, and of the efficacy of both" (p. 833).

The end results of lay consultation were support, information processing, the acquisition of new information, and support for action. Furstenberg and Davis found that there were definite norms about talking about illness and with whom this was an appropriate activity; men tended to talk casually to their wives in a reporting style of conversation, whereas women tended to have a wider network of people with whom they discussed their health. Those who trusted and had access to their doctors had no need to seek advice from a lay network. This is a very small study and certainly no suggestion is made that any generalisations can be made from it but it is helpful in showing both the "everyday" nature of lay consultation which may make it disappear from significant memory as well as perhaps indicating why so many people may move directly from Solo navigating to Navigating by consulting a pilot.

Navigating by direction

For a number of solo navigators their chosen course was seriously questioned by the incursions of "significant others" into their trajectory paths. They themselves remained quite unconcerned about their progress and would not have considered consulting a doctor at the stage of the uninvited challenges to their competence. The following incidents give a flavour of the types of "direction" given:

- A son caught sight of his father's leg wound when he was passing his bedroom door. The son reported what he had seen to his mother who then tackled her husband and pressured him into seeking medical help.
- A wife of a man who had self treated for six weeks said that she found out about his wound because its smell was offensive. The man, however, was adamant that he was proceeding according to his trajectory and replied emphatically: "well it was healing!"

- A man who noted that his wife had been applying bandages to her leg for three months asked one day: “What is that plaster you’re wearing on your leg? You’re forever wearing it. What have you got?” Again, on seeing the wound he advised that she seek medical treatment.
- Two friends of a lady who had been self treating a leg wound for months cornered her one day and advised her that if she had a leg ulcer “She had best not mess about with it but get on up to surgery”. In this case, both friends had leg ulcers and felt that they could speak from a position of expertise.

However, the advice given was not directly recognised as being responsible for movement towards the general practitioner. For example, the husband who had asked why his wife was wearing a bandage indicated on interview that when he saw it and advised consultation “it was a proper ulcer”, but she was not convinced that she required medical intervention. In fact, she sought the opinion of the village chemist: “So I went to the chemist rather than go to the doctor and the chemist said: ‘I can’t give you anything for that, you must go to the doctor’. So then, **of course**, I went to the doctor.” It was this, more professional opinion, that was a deciding factor for her. The advice within this arena of navigating was helpful but when it came from other lay people, other solo navigators with no particular expertise, it could be listened to but ignored. The navigators with this condition were very much self directed and the advice they sought, had more influence than that given.

Navigating by pilot

However, eventually every one of these navigators admitted the need for an expert pilot to guide them through a particularly problematic phase that was marked by one or more of three properties: a) pain, b) deterioration of the wound or c) length of time from the ulcer onset. There was a reluctance to “bother the doctor” with a trivial complaint and for many, even at the time of consultation, there was doubt that they had made the correct decision. Pain was a deciding factor that many patients remembered as the trigger for

consultation: "I went because my legs hurt" , "It began to get rather painful", "I was in such agony", "It was the pain made me go. In fact it made the ankle bone swell a bit...I had to have something done to ease the pain". For others, the deterioration stood out as the key factor and comments such as these were typical: "I could see it was not right", "It was getting bigger and leaking", "It just didn't get better. You think it's nothing and you leave it and of course, it didn't get better and it got worse.", "It gradually got bigger and bigger and harder", "It got browner and it started to weep". The length of time appeared in retrospect to have been the deciding factor for others: "Well, it never healed up for....it would be twelve months. It never healed up so I went to the doctor's.", "It just went on and on and on and I thought I better go to the doctor with it. That would have been about fourteen weeks after it started, like.", "Well, as I say, I couldn't heal it up myself; I knew I needed something else."

The underlying key symptom that all remembered vividly was the pain. Pain was their experience and the wound was their evidence, the sign of pathology that helped them to legitimise their decision to consult. The decision to seek a pilot was not an easy or straightforward one for any of those whose wounds developed from minor trauma or spontaneously. They sought a pilot for a temporary phase and this is clearly indicated from their comments at interview; they did not anticipate a long period of being out of control of their health course.

- "I went to the doctor to see what they could supply me with" said one gentleman who thought a prescription would be all that was required of the professional pilot.
- "Well I thought they might have some more modern treatment for it. I'm a nurse myself so I could dress it, I thought."
- "I just wanted summat for the pain, really, that were all."

It was the rare navigator that regained control of his course quickly. One lady tried a prescription ointment from her doctor and when that did not work

she resorted to solo navigating. The doctor never knew that his prescription had not been effective:

“I went and he gave me some sort of cream. I can’t remember the name of it now but it was plain; it had no antiseptics or anything like that in it at all. But it didn’t do them a bit of good. It didn’t touch them. It didn’t heal them a bit.”

This one exceptional lady avoided losing ongoing control despite episodic ulceration. One might be tempted to imagine that her case was unique perhaps because pain was not a prominent symptom for her but this assumption would be wrong; she suffered considerable pain but was able, in Alonzo’s terms to “contain” it within her lifestyle. She also, had experiential knowledge that the doctor was unable to alleviate her symptoms. Her case confirms the findings of Segall and Goldstein (1989) who found that the belief that medical care was ineffective led some of people to self-treat. In addition, her uncertainty had been decreased because the doctor had seen the wound, diagnosed it and given her a treatment she could manage.

However, over time, many people with leg ulcers found the treatment to be either ineffective at achieving healing or as problematic as their own efforts had been and yet most did not remove themselves from professional navigating. Most simply could not, either because of the levels of disruption to their normal lives they were experiencing in the acute phase or because the treatment prescribed was of such complexity that self care was unthinkable. Most became “chronically ill” without knowing that it was happening. The nature of the consultation with the general practitioners will be discussed next before moving on to examine the experience of these patients with their nurses.

Section C Professional piloting: the general practitioner's role

"When a patient consults a physician, he or she does so with one specific purpose in mind: to be healed, to be restored and made whole, i.e., to be relieved of some noxious element in physical or emotional life which the patient defines as dis-ease--a distortion of the accustomed perception of what is a satisfactory life" (Pellegrino and Thomasma, 1981 p. 122).

The purpose of the clinical encounter is restoration and healing and this end is arrived at through a process of clinical decision making that entails choosing the right action for each individual patient. The goal of medicine is therefore "irretrievably personal" (p. 124).

The general practitioner has a number of opportunities to shape the trajectory of his patients who present with leg ulcers. His approach to them will be influenced by his knowledge of the underlying pathology and his awareness of treatment options available to them. His proposals for shaping the patients' experience will be based upon his trajectory projections and his familiarity with and acceptance of the commonly utilised trajectory schemes. The initial step of trajectory management is usually the determination of the medical diagnosis through the clinical encounter:

"Diagnosis is the health professional's term for the beginnings of trajectory work. To do anything effective, other than just treat symptoms, the illness has to be identified. Once that is accomplished, the physician has an imagery of the potential course of the illness without medical intervention. The physician also has the mapping of what the interventions might be, what might happen if they are effective, and what resources are required to make them" (Strauss et al. 1985, p. 20).

In short, the medical diagnosis allows the physician to have a trajectory scheme.

The plan of action that is expected to follow from the medical diagnosis usually involves specific interventions carried out in a specific sequence with the purpose of controlling the present or anticipated developments in the disease experience (Strauss et al. 1985, p. 23).

There are situations in which the diagnostic role of the doctor lies in determining the *symptom* rather than the *condition specific* diagnosis and these have been discussed. To summarise that discussion it might be said that medical diagnosis at the *condition specific* level is waived in those conditions where it would be of little value in directing treatment. It is undeniable that the well-being and safety of the patient rest upon the fine clinical judgment of the physician. If the doctor directs his efforts towards determining the condition specific diagnosis when the symptom specific level would have sufficed, the restoration of the patient to health is jeopardised or delayed as time is lost and remedies withheld pending confirmation from tests and investigations.

Determination of the diagnosis at either the condition or symptom specific level is the necessary precursor of a treatment plan. "Patient preferences are the ethical and legal nucleus of the patient-physician relationship" (Jonsen et al. 1992, p. 37) and therefore, the doctor is at least morally required to make a complete disclosure of the treatment options available to his patient and his rationale for recommending one form of treatment above another. Only when this has been done can the patient be said to be in a position to give informed consent or to have a preference for treatment. If the doctor lacks knowledge of the condition and proceeds with a treatment plan based on unnecessary uncertainty then he could be said to be failing in his duty towards his patient:

"The physician's central responsibility is to use medical expertise to respond to the patient's need for help. That need is usually expressed by a patient's request to learn the significance of physical signs and symptoms that disturb physical well-being and to have those disturbing signs and symptoms relieved and the underlying disorder cured" (Jonsen et al, 1992, p. 17).

Doctors suffer from the stresses of uncertainty in their encounters with patients. A recent large scale quantitative study by Gerrity et al. (1992) found that doctors in family medicine expressed feeling more uncertainty in their work than their counterparts in any other specialist field with the exception of psychiatry. However, the potential effect of a poor clinical judgement on the patient might decrease or increase the level of stress felt by the doctor. For example, in the case of the patient with chest pain, a misdiagnosis might

endanger a life, and the doctor's stress would be expected to be greater than in the case of the patient with a leg ulcer for whom a poor diagnostic judgement would provide opportunities for innumerable revisions. It may be that the relative unimportance of a wound allows the doctor to remain relaxed about his own lack of knowledge and unmotivated to gain the expertise to help these patients. In addition, as Gerrity and her colleagues found, doctors fear inadequacy and failure, and perhaps in situations where they lack expertise, they prefer to avoid the potential for failure wherever possible. Custom and practice in leg ulcer management mean that the general practitioner can refer the patient to his nursing colleagues for care without ever facing the uncomfortable decisions and uncertainty head on.

The recommended medical approach

The doctor should be aware that condition specific diagnosis is required for proper trajectory management of the patient who presents with a chronic wound on the lower leg. The initial consultation is likely to be a lengthy one because the differential diagnosis of a leg ulcer is by no means clear cut in most cases. Browse, Burnand and Thomas, internationally recognised experts in the field of venous disease, state: "leg ulcers are so often a manifestation of distant disease (that)...*a complete medical examination is essential in all patients*" (1988, p. 372). In order to assist in the process of medical diagnosis a number of additional tests need to be carried out and it will take time for some of the results to become available to the doctor. Tests that might be ordered include: doppler assessment of the venous and arterial systems of the lower leg, blood tests for indications of anaemia and diabetes and wound swabs for the identification of infecting organisms. In addition, the medical practitioner would plan to obtain a referral to a specialist, as appropriate in order to arrange for the surgical or medical interventions that would assist in the maintenance of healing. The recommended methods of preventing recurrence include: sapheno-femoral or sapheno-popliteal ligation, with or without ligation of the communicating veins, deep vein bypass or reconstruction, sclerotherapy, elastic stockings, fibrinolytic enhancement and permanent compression of the lower limb (Browse, Burnand and Thomas, 1988 p. 431).

Having determined a tentative condition specific diagnosis the doctor would be most likely to refer the patient to his nurse for wound dressings and for other nursing care, that is, for care directed towards dealing with the patient's responses to his illness and for which he wished "supportive assistance."

The approach in practice: the onset of professional navigation

In this study fourteen general practitioners were interviewed in order to determine their approaches to the management of patients with leg ulcers. All admitted that they did not know how to deal with patients with this problem and therefore were quite *pleased to be able to refer them to their nursing colleagues* after prescribing the appropriate drugs for pain or infection. None was able to *carry out even the most basic doppler assessments of arterial function*. None mentioned undertaking complete physical examinations as part of their initial consultation and subsequent questioning of their nurses and patients indicated that this was never done; examination was always limited to the ulcer.

The doctor aims for and achieves symptom specific diagnosis because he is not aware that anything more is required; the patient simply has a "nasty" or "chronic" wound that is adequately labelled as a "leg ulcer". The way in which the doctors handle the care of these patients is reinforced by the actions of the nurses who accept them usually without question with this level of diagnosis. It is the custom and practice in Britain to send patients with wounds to the nurse because "she knows more about that sort of thing" as many doctors interviewed for this study stated.

The nurse's expertise in wound care is widely recognised. Allen, a medical authority in leg ulcer management has written that:: "More and more doctors—and rightly so—are handing the care of wounds over to their colleagues of the nursing profession" (1990, p. 409). It may seem unbelievable that medical practitioners, when faced with what is, after all, a common problem, should demonstrate such a low level of knowledge of the appropriate diagnostic requirements and suitable trajectory management. However, a

review of the international literature reveals that condition specific diagnosis is rare. Negus(1991), a medical expert on leg ulcers in Britain stated :

"Energetic attempts to heal ulcers and to prevent recurrence are often unsuccessful due to the failure to appreciate that diagnosis and treatment of the underlying cause of the ulcer is very much more important than treatment of the ulcer itself"(p. 53).

Similarly, Burton(1993), a dermatologist working in the United States of America, wrote:

"Unfortunately because a proper approach requires a multidisciplinary view that few of us are exposed to in our training, we enter practice without a clue about managing the ulcer patient" (p. 315).

Further confirmation that medical practitioners routinely fail to provide condition specific diagnoses for patients with leg ulcers is clearly reflected in the international nursing literature. A typical referral to the community nursing service in Vancouver, Canada in 1987 read: "leg ulcer, daily visits, do what you think best" (Lanyon et al. 1987, p. 34). The American nursing literature confirms that nurses, not doctors, are engaged in the process of diagnosing the ulcer type, that is, in determining the condition specific diagnosis. Cuzzell (1994, p. 34-35) in an article dealing with wound assessment skills for nurses, notes that: "The first step in treating a leg ulcer is determining its underlying cause" and she then continues with a description of arterial and venous wounds with the aim of helping nurses to differentiate between these two major types. Similarly, in Australia, a group of community nurses wrote that: "On average, each month, 600 people with a *primary diagnosis of leg ulcer* are in the care of the Royal District Nursing Service" (Bennett et al. 1985, p. 36). In Britain, further evidence confirming that nurses do in fact attempt to identify the causal factors, that is, to determine the medical diagnosis, is found in the writings of key nursing authors. Ertl(1992), a nurse who has published a number of articles on the subject of leg ulcers in the nursing press, wrote:

"Only when the principal aetiological factors, the patient's general condition, and the specific characteristics of the lesion have been determined, can effective treatment commence. This requires diagnostic

skills usually associated with doctors, but it has long been suspected that this responsibility is generally left entirely to the DN" (p. 546).

Cameron (1991) in her article published in the nursing press and entitled: "Using Doppler to Diagnose Leg Ulcers" focuses on the importance of accurate diagnosis and it is clear from her statements that it is, in her opinion, the nurse's role to determine the diagnosis; her advice is presented as a series of points for the nurse to follow, for example: "First, feel for a foot pulse..."(p. 26). Although Cornwall (1991, p. 36) in her article on the subject of the management of venous leg ulcers, appears to use the term "assessment" and "diagnosis" interchangeably, it is unquestionably the diagnosis of ulcer type to which she is referring. In short, it is the normal practice for patients who present themselves to their general practitioners to receive, at best, the symptom specific diagnosis of "leg ulcer." The nurses would not be attempting to fill this diagnostic void if the medical practitioners had provided them with a condition specific diagnosis.

The research team in the Lothian and Forth Valley study, having uncovered evidence of poor medical management, suggested that to improve the situation of the patient with a leg ulcer it might be advisable to provide a "centralised diagnostic and advisory service" for the primary care workers. Their very diplomatically couched conclusion that: "Few doctors see a sufficient number of patients with leg ulcers to develop expertise" (Callam et. al. 1987a, p. 1391) seems to have gone unheeded. However, the problem cannot necessarily be said to rest primarily on a lack of professional expertise on the part of the general practitioners; the core difficulty may be a lack of awareness of the importance of condition specific diagnosis. The doctors view the patient with a leg ulcer as a patient with a chronic wound and they do not demonstrate evidence, as a group, of appreciating, as Negus(1992) stated, that uncovering and dealing with the cause is more important than dealing with the ulcer itself. If they did recognise the need for condition specific diagnosis they would have two options: to gain the expertise or to refer their patients to those who had it. Callam and his colleagues (1987a, p. 1391) noted that patients were referred to consultant clinics in other situations where the diagnosis or management were deemed to be difficult but remarked that this pattern was not customary in the case of the patient with a leg ulcer. Their finding is in keeping with the study of

Lees and Lambert (1992) who examined the prevalence and management of patients with leg ulcers in the Newcastle area. They found that only 35% of their sample (N=175) had ever been examined in hospital for their ulceration and of these only 7% were seen by a vascular surgeon. Of the remainder 21% were seen by a dermatologist, 5% by a diabetologist and 2% by other specialists (p. 1032). It is important to note that the highest number of referrals found in this study was to the dermatology department and this finding provides further evidence that leg ulcers are deemed to be skin problems and that the underlying causes are not fully appreciated. Cornwall and her colleagues(1986, p. 694) in Harrow, Middlesex found that of their sample of patients with leg ulcers (N=357) "62 per cent had never been referred to a hospital and after initial visual or verbal diagnosis by the GP were subsequently managed by the district nurse." It should be noted that they are giving considerable evidence of the diagnostic process in their statement: "visual or verbal diagnosis by the GP". It is clear that full medical assessment is lacking. In the Edinburgh and Forth Valley survey (Callam et. al. 1985, p. 1856) it was found that 87% of the sample of those with leg ulcers (N= 1311) were managed by the primary health care team; only 13% were wholly under hospital care. The alarming recurrence rate of over 67% and the number of episodes of ulceration of three per person in a nine year period led the researchers to suggest that more attention should be paid to prevention (Callam et al. 1987a, p. 1391).

It is this lack of expertise and knowledge that appears to contribute in a crucial way to the subsequent anomalous management of "leg ulcer patients" by nurses. The lack of definition of the patient's medical problem by the doctor leads the nurses to attempt to fill that diagnostic vacuum in order to obtain the detail they require to give direction to their clinical practice. The effect of the medical approach is a distinct, almost unique shaping intervention. In no other situation does a medical practitioner routinely give a symptom specific diagnosis and expect the nurse to whom he has made the referral to manage the patient with an essentially unknown condition. The doctor is acting as a professional pilot, who, after steering the course beyond the most immediate visible obstacles, simply abdicates responsibility to other pilots who lack his skills to carry on the piloting function required.

Conclusion

It is the doctor's duty to exercise his professional judgment in such a way that he optimises the benefits to his patients and minimises the risks. He must ensure that serious and treatable illness are not missed but are uncovered through the use of appropriate tests and technology(Pellagrino,1981, p.137). The goal of the medical encounter is the restoration and healing of an individual and only those approaches and actions that reasonably support those ends can be deemed appropriate or ethical. It will be shown in the following section on the subject of Nurse navigating that the pattern of care that begins with the doctor becomes increasingly detrimental to the patient.

Section D Professional navigating: nurse shaping

Introduction

Nurses have a unique role to play in shaping the trajectories of the patients in their care. Their particular contribution comes from the goal of nursing, which, as described within the chronic illness trajectory framework (Corbin and Strauss, 1992, p. 20-21) involves helping patients to shape their illness course while also maintaining their quality of life. This end is achieved through supportive assistance, that is, through the process of piloting, which in its aim and focus is very much in keeping with the definition of nursing developed by Henderson (1966) and later adopted by the International Council of Nurses:

"The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible" (p. 15).

This definition helps to elucidate the differences between shaping through piloting as practised in medicine and within the context of nursing. The nurse's shaping activities are connected to the responses of the patient to his illness; the doctor's to the disease process. Piloting by registered nurses occurs within the discipline of nursing and is expected to conform to the Code of Professional Conduct as set by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1992).

The organisation of nursing care

The patient, although unaware, at the point of referral to the nurse, has already begun his patient career. His care is not going to be managed by the medical pilot but instead by the nurse who in these circumstances, will assume the navigating role. He will be in passage for a long time and to manage this: "He is put into a transitional status, or a sequence of them, that denotes a period of time during which he will be in a status passage" (Glaser and Strauss, 1968, p. 237). The person moves from the status of solo navigator to patient, and from the status of a patient who requires medical care to that of a patient who is in the care of a Practice or District nurse. His

status may also change to be that of a patient in the care of the dermatologist. Each status is somewhat different and varies with the knowledge of the carer, her expertise and approach to management. The patient will be moved within the health care system "as his trajectory is redefined or as he reaches certain critical junctures in an anticipated or defined trajectory"(p.239). The "structural process", that is, the complex interaction of the structural elements of the particular sector of the health care delivery system with the care given to the patient can have a powerful impact on his career as a patient(p. 237-239). The "sentimental order" of these settings can be quite different one from another. In most cases, in the early stages, the medical work is done by relative strangers and in conditions where there is some danger to the patient. The medical aspects of trajectory work usually take priority over the sentimental work and unless there is a pressing reason for noting pertinent information about a patient's biography or self concept, these features are often relegated to positions of lesser interest and importance. There are a number of types of sentimental work; listed by Strauss et. al.(1982, 258) they include interactional work, trust work, composure work, biographical work, identity work, awareness context work and rectification work. Some of these will be expanded as the findings are presented and discussed.

The Practice Nurse, because of her location at the general practitioner's surgery, is the most common initial point of referral after the doctor has initiated symptom specific treatment. Although still technically in the care of the doctor, the delegation of treatment and care to the nurse gives the ongoing management new meaning. Whether the patient remains within the care of the Practice Nurse depends on two factors: his mobility and the length of time required to attend to his dressing. With the development of general practice and the growth of GP fundholding, the time of the Practice Nurse as a member of the practice team has come under increased scrutiny. If a patient is not able to visit the surgery with relative ease, he is of course referred to the District Nurse for care in his home. Similarly if his care is likely to be prolonged in duration or take an inordinate amount of the nurse's time within a surgery setting, then that patient too will, usually, be referred to the District Nurse. One Practice Nurse recalled the case of a man whose leg ulcer was

proving to be difficult to heal and time consuming to dress: "I found the doctors were saying, you know, 'Let the District Nurses go in now'. With this new contract that's how it works." Another elaborated:

"If possible they (the doctors) refer them to the District Nurse because they are time consuming particularly in a practice situation. So if we get one that's not healing or that would be getting worse and it was inconvenient for the patient to come, we would sort it out with the District Nurse if possible. The doctors prefer the ulcers to be dressed by the District Nurse—not because they are any better, but because they are so time consuming in general practice."

Note here how complex work or downward phasing is handled. Rather than respond to this change medically, the patient is removed even farther from the general practitioner. The net result of this system of management means, of course, that the Practice Nurse is more likely to deal with the younger, more mobile patients with "newer" ulcers who are more likely to respond quickly to appropriate care. The District Nurse, by contrast, is more likely to be asked to care for the older, more infirm, less mobile patients with complicated trajectories.

Referral to the consultant clinic can come about at any point but it occurs most often when marked symptoms and signs of deterioration develop. The consultant clinic, then, is expected to handle the most complicated trajectories of all. Referral to the consultant does not remove the patient from the care of the nurse but it removes the control of care and management from her. The consultant clinic staff make decisions regarding treatment and the District Nurse is expected to carry out their prescribed treatment between clinic visits. Despite the fact that referral to the consultant is always a possibility, it is an option not routinely taken. The possible process of the patient through the health care system is shown in diagram 25.

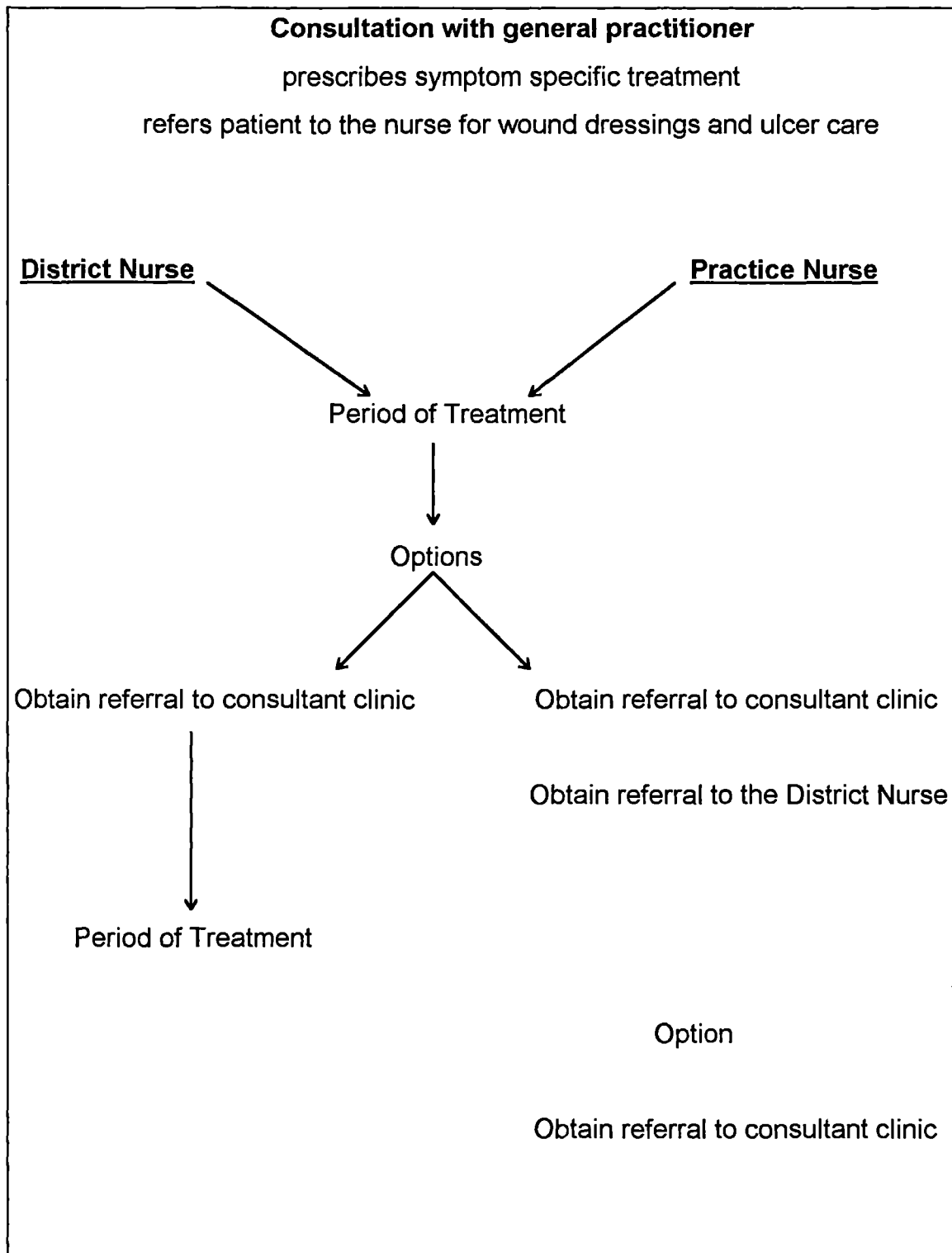


Diagram 25 The potential process of the patient within the health care system

Professional preparation of the nurses to shape the trajectory of the patient with a leg ulcer

In this study, the District Nurses and Practice Nurses interviewed had different preparation for their role in the management of patients with leg ulcers and therefore each group will be dealt with separately. Some of the District Nurses had undertaken the formal District Nurse training at university after the 1981 revisions to District Nurse Training had been introduced, whereas, others had qualified as District Nurses prior to this date and had undertaken the shorter day release scheme. The majority from either type of training indicated that they had learned how to manage wounds primarily through "on the job experience". All indicated a secondary source of knowledge such as attendance at study days, reading wound care or nursing journals, or information given by representatives of pharmaceutical companies but the basis of their present practice was experiential and gained in the context of the community nursing care network. Nurses working on the district have regular contact with their colleagues, often sharing an office or base and because of the pattern of their work, it is inevitable that they "cover" each others' caseloads during holidays, sickness, and study leave. This arrangement means that a number of nurses gain knowledge of the same group of patients and discussion of their care back at base is common. This context of professional case management tends to be viewed very positively and comments indicating that the others in the group are a source of updating or assistance are common: "We use each other as a resource, really", and "There was this super nurse I worked with in Peterborough—she always got her leg ulcers healed!", and "Well, Marion is our expert on leg ulcers in this clinic. If I'm stuck I talk to her."

Remarkably, it is rare to discover any nurse who is able remember having been taught wound care during her general training and even during District Nurse training the amount of coverage of the subject area is described as very limited. Older nurses who undertook the shorter day release schemes did not have the management of wounds or the patient with a leg ulcer included in their formal preparation and they indicated that they received little

personal tuition or supervision from their more senior colleagues. One who trained as a District Nurse in 1972 said:

"And really any training and education I've had has been through reading journals and attending the odd study day, and listening to the drug reps. And with the drug reps--well, they give you the solution from their side and it's always absolutely fantastic. It's only once you go out and try it that you discover that you've got a problem: it doesn't always work."

Those who had undertaken their training later had not fared appreciably better:

"I haven't had any teaching really. Certainly not during my (general nurse) training (1970) anyway. I asked Sister X yesterday if she had and she said 'No'. As far as I remember as a student or a staff nurse, I didn't see a leg ulcer. Having never seen one I can't think I was taught to treat one or diagnose or even think about one"

Remarking on her subsequent District Nurse training (new training:1984) she added:

"Well, the first time I came across leg ulcers was in the community. My Practical Work Teacher taught me the principles of dressings really and what we were trying to do. And she taught me the principles of bandaging. She was very good really"

One nurse, who recalled formal preparation during her university training went on to describe pharmaceutical company/product based classes and concluded: "We had literature on the subject, but I can't remember any tutorials on the subject."

It is unusual to find a District Nurse who felt well prepared by her training for her future role in relation to wound care. Occasionally however a chance occurrence is described as quite beneficial in this regard. For example, a nurse who trained as a District Nurse in 1987 said:

"I had quite a bit of input really: one of the District Nurses I worked with had done a course in London and worked with a doctor who specialised in leg ulcers and treatments. So she brought the knowledge back as well into the team...and I suppose we had constant input because it was a topic of conversation at all times: 'How was somebody's ulcer doing?'"

The lack of preparation for their role in the care of patients with wounds is surprising but it is not atypical. Thomson (1993) states that:

"Community nurses are given little or no training in the management of leg ulcers—most of their knowledge is gained from personal study, trial and error in practice, peer support or indeed wound product representatives"(p.82).

Roe and colleagues (1993, p. 303-304) note that District Nurses who qualified after the introduction of the new syllabus of training in 1981 are more likely to have attended a course covering the subject of leg ulcers but the quality of assessment and the advice given to patients is not routinely sound: pain is not assessed by fifty five per cent, pulses are not always checked, forty one per cent inappropriately advise their patients with arterial ulcers to elevate their legs, wounds are measured by less than half the sample. They conclude that there is a "need to improve community nurses' knowledge of the aetiology and research based management of patients with leg ulcers"(p. 305).

The Practice Nurses, as a group, had either entered this area of nursing directly from hospital based work or on return to nursing after a break in service. They share with their District Nurse colleagues a lack of formal preparation in wound care but their situation is often exacerbated by having, in many cases, no other nurse in the surgery setting with whom to confer. Even in surgeries where a number of nurses are employed, the pattern of work is such that overlap is rare and opportunities to discuss patients is limited. Those who recalled their hospital experience usually indicated that it was of limited benefit in preparing them for the care of the patient with a leg ulcer, being frequently in areas of work where they were uncommon. Some, but not most, had taken the formal "Practice Nurse Course" at the local university but even those could not recall any details of educational exposure to the subject of wound care/leg ulcer management.

Knowledge of the care of patients with wounds or leg ulcers is gained by trial and error: "You get it by experience and seeing different patients." Some

feel that if they have a problem in caring for a wound, (this terminology is used advisedly) they could ask the doctor to take a look at the leg. However, most express the belief shared by their District Nursing colleagues that : "I know more about leg ulcers than they(the GP's) do" and therefore consultation is considered to be essentially unhelpful. This view recurs frequently and helps to explain why, as a group, the nurses continue to care for patients with conditions that they, as nurses, poorly understand. Given the alternative of being cared for by the doctor, the nurses firmly believe that the patients are receiving better care in their hands.

Given the lack of formal preparation for the role of caring for the patient with a leg ulcer one wondered how their practice conforms to the expectations of the United Kingdom Central Council for Nurses, Midwives and Health Visitors: the regulatory body responsible for the standards of these professions. As all registered nurses are professionally accountable for the care they provide, each has a personal responsibility for ensuring that her care is based upon current knowledge. The Code of Professional Conduct (UKCC, 1992) states that:

"Each registered nurse, midwife and health visitor shall act, at all times, in such a manner as to: safeguard and promote the interests of individual patients and clients; serve the interests of society; justify public trust and confidence and uphold and enhance the good standing and reputation of the professions"

The Assistant Registrar of the Standards and Ethics Committee of the UKCC in 1993 stated that:

"in matters of wound care, as in all other aspects of professional practice, you are accountable for your decisions and for the manner in which you execute them" (Payne, 1993, p. 6).

If the nurses have not received in depth formal preparation for their role how do they manage in actual clinical practice?

The nurse's role in diagnosis: strategies for dealing with ambiguity

As has been mentioned previously in the section relating to medical shaping, the nurses concerned with the care of patients with leg ulcers are indeed trying to diagnose the ulcer type. Essentially, they are attempting to differentiate between arterial and venous ulcers, the two categories that account for over 90 per cent of ulcers. This is the key distinction that is aimed for and this is reflected in the literature and in the findings of this study. There is a general awareness that this distinction needs to be made because of the crucial differences in treatment: the arterial ulcers must not be compressed but those of venous origin benefit from some degree of compression in order to reverse, at least partially, the superficial effects of venous hypertension that give rise to the ulcer.

All nurses are aware that they are attempting to determine the nature of the underlying pathology, but few are completely comfortable with this diagnostic role. There are four main strategies employed to deal with the ambiguity of their situation and minimise their anxieties in acting beyond their expertise: standing together, standing behind the doctor, standing at the end of the line and standing behind technology.

In the strategy of *standing together* the nurses express the view that this is a normative role expectation for District or Practice Nurses. They could be said to be doing their best and they do not express concern over the critical decisions they were making. The following examples illustrate this stance.

"We just 'look diagnose' them. When a patient is sent through to see me I would say: "What do you think it is? What has the doctor told you? Did he suggest any treatment? Or did he say: 'Go see the nurse; they know better than the doctor anyway' ?"

It is interesting to note the use of "we" rather than "I" and this distinction is characteristic of this strategy: this is the pattern of referral in her surgery and she takes her cue from that and the assumption that "we" do it in this manner. Another Practice Nurse stated:

"In a perfect world we'd get doppler measurements but we don't have all that technical information about the patients legs and their

circulation and blood supply. You have to do it on just 'What you see is what you've got really!'"

Like so many others, this practitioner readily admits that this is far from ideal but she remarked later in the interview that nurses know far more about wounds and wound care than the doctors and that the patients are really better off in their care. This view is reflected in the words of another nurse:

"We don't have a doppler or anything like that, you know, to test out. I think it's mainly us nurses who pick things up from different sources and listening to different reps and giving things a try really. The doctors here would probably say: 'What's the difference between a venous and an arterial ulcer?' and as regards treatment: 'What's the difference?'"

The Practice Nurses at that surgery do their best to determine the ulcer type by their own assessments and the response of the ulcer to compression. At another surgery a Practice Nurse remarked:

"I have always been a bit confused between--this sounds silly coming from a nurse--between arterial and venous ulcers. You just never get down to the nitty gritty do you, of actually deciding."

She went on to say that "We definitely put compression on when we first start dressing--definitely". In effect, the patients are treated *as though* they had venous ulcers. The compression bandage that is used would be sufficient to cause problems for patients with arterial compromise. Here it is interesting to note "you never.." instead of "I never". Similarly, a District Nurse remarked:

"I don't know how to use a doppler. I go on the actual appearance of the ulcer, the state of the rest of the leg. I don't find it easy to get foot pulses but I try. I tend to look at the medication the patient is on--often the medication will lead you to conclude what problems the leg has got. I look to see if they have got white legs or generally cold feet--but you don't get a nice venous ulcer. You do not get a nice arterial ulcer. You very rarely get the "classic ulcer"--it's lovely when you do! But when you don't I think you've got to play it safe."

"Playing it safe" means that treatment is managed by cautious trial and error: the end result is prolonged morbidity and lengthy healing times or simply perhaps the development of chronic wounds. Despite the lack of certainty there is not the slightest suggestion that the patients would be referred on to a consultant or back to the general practitioner: the patient is dealt with by the best means possible from the nurse.

In all cases the diagnostic distinction is made or at least attempted and in almost every case it is based on the limited visual information and verbal descriptions available. A very interesting variation of *standing together* is illustrated below. In this case the nurse actually stated that she preferred the doctors to leave the diagnosing to the nurses:

"I think if a doctor is going to diagnose, he has to do it right and if he isn't going to diagnose then at least you've got the chance of leaning round that way. I'd rather they say nothing than get it wrong....I would rather them say 'Go and sort it out'...If they know where their limitations are and historically we know about dressings and doctors don't—so if they steer clear we have a free rein so to speak."

In *standing behind the doctor*, there is an attempt to abdicate any accountability for personally performed nursing functions because the doctor has made a decision and the nurse is simply following his orders or suggestions:

"I'm probably different to the others because I don't like to take on the diagnostic role. I DON'T think it is my remit. I therefore often arrange for a GP to come in with me when that dressing is down—and yes, I will suggest treatment BUT he is authorising that and he has seen it."

Another stated:

"And they're quite happy for us to sort it out, but for our own—sort of satisfaction —we've got to get the backing."

In *standing at the end of the line* the nurses express the view that they do not in fact make a medical diagnosis because they are merely accepting the word of the previous doctors or nurses as presented in medical and

nursing records. In these cases, as in *standing behind the doctor*, the nurses appear to be unaware that their own accountability as professionals is not relieved by this stance. The following two quotations typify this approach to management:

"I find it very hard to say at times if its venous or arterial. I must admit, I look at what notes have been made and what assessments have been made previously and draw my conclusions from there...."

The District Nurse in this case knows that treatment should be linked to the specific cause of the ulcer and she recognises that she is working in the dark. Without the information she requires, she sees no other remedy to standing at the end of the line taking no part in making current assessments.

The Practice Nurse whose statement gave this category its code stated that she was:

"at the end of the line of ulcers. If they are very bad they have been treated at home by the District Nurses who would have initially made that decision"

In her case she thinks that as she is following tried and tested treatment for conditions that have previously been diagnosed at the condition specific level by another nurse.

The strategy of *standing behind* technology is a limited one because, as may be seen from the previous comments, the majority of nurses have neither the training to use a doppler nor access to one. However in the course of data collection two District Nurses were found who had obtained dopplers: one from her surgery and the other from local fundraising. The later had taken a personal decision to gain more skills because of an experience she had in the course of her duties. She had been approached by a drug company and asked to enter some of her patients into a clinical trial of a new dressing. She chose for the trial her most difficult to heal ulcer patients. One of these patients was a man whom she had been treating for five years for what she

was certain was a venous ulcer. She had been applying compression but had not seen an improvement:

"They didn't get better but they didn't deteriorate--for five years I tried to get them healed up. One day I arranged for a clinical trial rep to see him and take doppler readings. The reading indicated real arterial problems: I took the compression off and his ulcers healed within three months!"

She found this to be a critical incident in her career. When interviewed in the course of this research she had learned to use the doppler and had assumed responsibility for taking ankle/brachial index measurements on all patients with leg ulcers in her District Nursing team.

The Legitimacy of the Nurse's Role in Diagnosis

Whereas it has developed into custom and practice for nurses to assume the management of patients with leg ulcers, their role in attempting to determine the basic underlying pathology, that is, the knowledge required if they are to do any more than merely treat a surface wound, is professionally indefensible. Whereas the UKCC does not limit the scope of practice, it does provide clear principles that guide the professional when moving beyond the realm of conventional nursing practice:

"The principles which should govern adjustments to the scope of professional practice are those which follow. The registered nurse, midwife or health visitor:

- 9.1 must be satisfied that each aspect of practice is directed to meeting the needs and serving the interests of the patient or client;
- 9.2 must endeavour always to achieve, maintain and develop knowledge, skill and competence to respond to those needs and interests;
- 9.3 must honestly acknowledge any limits of personal knowledge and skill and take steps to remedy any relevant deficits in order effectively and appropriately to meet the needs of patients and clients;

9.4 must ensure that any enlargement or adjustment of the scope of personal professional practice must be achieved without compromising or fragmenting existing aspects of professional practice and care and that the requirements of the Council's Code of Professional Conduct are satisfied throughout the whole area of practice;

9.5 must recognise and honour the direct or indirect personal accountability borne for all aspects of professional practice and

9.6 must, in serving the interests of patients and clients and the wider interests of society, avoid any inappropriate delegation to others which compromises those interests" (UKCC, 1992, p. 5-6).

Considering what has been said about the preparation of the nurses for practice in the area of wound care and leg ulcer management, it must be accepted that their practice is outside the principles laid down by their professional body. The well being and safety of patients is endangered by their actions which are beyond the realms of their professional expertise. Nurses recognise that general practitioners are not knowledgeable in the care of the patients with leg ulcers and as a result they assume the roles of diagnostician and prescriber. When challenged, they reply that, they could object and refer the patients back to the general practitioner, but, in turn they ask: "What good would that do?" The view that the doctors are less than adequately prepared to deal with this group of patients is found both in the literature and in the field work for this study. A District Nurse summarised the views of many of her colleagues by remarking: "The GP's are certainly quite glad to get rid of them." Roe and her colleagues (1993, p. 304)) noted too that given that these patients are largely managed by nurses, referral back to the doctor would perhaps be insufficient action if a nurse had a concern relating to their care. Their view was that referral to a consultant would probably be required. Cullum, in an unpublished report submitted to the Department of Health (1992, cited in Roe, 1993, p. 300) is said to have been "concerned that all too often patients are managed entirely by the community nurse and are not given the benefit of an accurate medical diagnosis". The doctors have abdicated responsibility for this entire group and the nurses

have, over time, accepted this pattern of referral perhaps because it has developed slowly and from a time when referral entailed simply caring for a wound. One District Nurse encapsulated the present situation and how she thought it had developed:

"I think leg ulcers are a traditional District Nurse's job and I think it's a situation that has gone on virtually since Florence Nightingale's time. AND, it's going to take a long time to get a change of attitude. I don't know if it works the same for the Practice Nurses—I don't know if they do their own treating and prescribing or whether they actually get the doctor in. I would imagine, that like us, the doctor sends the patient through and says to use what they want to use."

Effective treatment of patients with leg ulcers pivots on a medical diagnosis and the present system of organising care for this patient group prevents this determination. It is not the nurse's normal role to assess patients for clues that will indicate the possible or probable medical diagnosis and yet this is routinely being done. Ertl (1992,p.544) clearly indicated that the 270 District Nurses in her study were actively engaged in data collection to make just this determination: their "differential diagnoses" were inferred from information provided. Mary Bliss,(1990) a consultant physician in geriatric medicine is perhaps the only medical voice raised against the current practice:

"Why are most doctors content to allow nurses to carry virtually the whole responsibility for skin wounds which they would not dream of doing for less severe, internal lesions? Is it because the skin is too easy to treat, or, perhaps more important, too easy to see? Or is it because it is too difficult and doctors have given up in despair?" (p.185).

She continues:

"The lack of assessment and supervision of wound management by doctors mean that all too often inappropriate techniques are applied by nurses who have neither the training nor the equipment to make important but difficult distinctions, e.g. between venous and arterial ulcers" (Ibid.).

She concludes that the existing dilemmas will only be resolved when doctors accept their responsibilities in relation to these patients and act collaboratively

with nurses and other paramedical staff to ensure that patients with chronic wounds (i.e. ulcers) are "properly assessed and reviewed" (Ibid.).

It is not in the best interests of the patient that he is referred without the level of diagnosis required: it wastes time, money, resources and costs much in terms of pain, interference with lifestyle, and deterioration of the patient's conditions. In all the field work done for this study, well over 800 nurses were asked if they had **ever** had a referral from a doctor with a condition specific level of diagnosis. Less than one percent indicated that they had known this type of diagnosis. There are virtually no voices within the nursing profession raised against the current custom and practice in relation to diagnosis. Moody(1993) states what should be occurring but her statement, like the comments of Roe et al.(1993) have apparently been overlooked by the profession:

"All patients should undergo a comprehensive assessment, which must include consideration of the underlying pathology and the implications of this to the integrity of the skin or the healing process. This is not to say that the nurse touches on the role of the medical practitioner; rather that the nurse seeks medical expertise and applies this knowledge to a final assessment"(Moody, 1993, p.6).

Effects of nurse's actions in the diagnostic quest

The inappropriate role that the nurses undertake in seeking a medical diagnosis that would underpin their nursing management has far reaching consequences. The patient at this point would have reasonably expected to have a medical diagnosis and to have been receiving treatment that would heal his wound. The arrangement of his care that follows referral to the nurse is not altogether in his best interests, but his initiation into the realm of nurse navigating is cloaked under the guise of a professional approach to wound management that has been arranged by the doctor. It is true to say that the awareness context is managed in such a way as to prevent the patient becoming aware of the undesirability of his referral; in many cases the nurse is not fully aware of the illegitimacy of her role in relation to these patients. The lack of awareness on the part of patient and in some cases, the nurse, limits the potential strategies that either could use to alter the course of the

passage. The ritual of dressing the wound links the patient and nurse and helps to perpetuate the arrangement of care. Whereas previously the patient could manage a simple dressing, now the dressing may be far too complicated for him to even attempt and whereas he might have trusted his ability to care for his wound at one time, his entry into the professional sector of medical care driven by the perception that his needs are beyond his abilities leads him to remain dependent.

The ongoing nursing and medical management of care will next be presented and discussed before focusing on the reciprocal impact of the condition and its management on the patients.

Section E Attitudes to caring for patients with venous ulceration

Each professional who deals with patients is influenced in some way by his attitudes towards the condition they have and their characteristics as a group. The general practitioner, for example, typically acts in a way that will meet the patients' most immediate needs and also deal with his lack of competence in caring for them in a condition specific way by referring them onto the care of the nurse. The nurses by contrast have attitudes that reflect either a general acceptance of their patients as individuals or they demonstrate a marked dislike to the group as a whole. Part of this bias has been seen in their readiness to believe that patients with venous ulcers are socially isolated individuals who tamper with their wounds and dressings in order to maintain contact with them. The bias goes deeper than that single stereotypical image and an entirely unexpected finding to emerge from this study is the degree of prejudice expressed towards those of the patient group who are older.

Although venous ulceration can affect people of all ages, the numbers of sufferers increases with age and it is common to find the group viewed together under the label of "old people". The number of derogatory or negative stereotypical comments made by the nurses about this group of people is truly staggering and warrants further attention. Approximately half of the nurses interviewed expressed an ageist bias.

The nature of the relationship between patients and nurses is at the very core of nursing. It is generally assumed that nurses view their patients as particular persons, not as simply part of a category and that they assess the needs of each person as a unique individual. The findings of this study, however, indicate that this view is not entirely accurate. Davis (1984, p.68-76) noted that nurses learn their social skills in small groups where there is great familiarity with the other participants. Upon entry into nursing, however, their individual interest in patients may be overtaken by the need to master technically difficult skills and to conform to group norms where the technical is valued above the interpersonal. In addition, the social pressures to take on group values may lead them to adopt the definition of patient groups made by more senior staff and the net result, Davis indicates, may be the labelling of

patients and the development of stereotypes. It is easy to see that the patient with a chronic illness and an ongoing need for nursing care might come to be viewed as an unrewarding patient, perhaps even labelled as noncompliant or difficult. This attitude might be seen as a defence mechanism to deal with the frustration associated with "non healing ulcers" particularly in nurses who neither understand the nature of the physical problem nor know the person as an individual in the context of a life lived outside the health care relationship.

There is considerable research evidence from a number of previous studies to indicate that nurses who work with elders have largely positive views of them (Taylor and Harned, 1978, Lookinland and Anson, 1995, Glasspoole and Aman, 1990, for example), and the contrasting findings in this study led to an exploration of the unusual nurse-patient relationship inherent in this anomalous area of nursing practice and a questioning of whether the assumption of a medical oriented role promotes a more negative attitude in some nurses. An alternative explanation is that the previous research is flawed by the use of convenience samples and therefore is not in any way representative. It is an area that deserves further study.

The work of Haight and her colleagues (1994) suggests that the resulting positive or negative attitudes of nurses might be based upon both personal relationships with elders and with exposure to well clients in the older age group. They explored the changing attitudes of eighty six nursing students throughout a three year baccalaureate program to determine whether the process of nursing education promoted ageism. The students were tested repeatedly: before and after exposure to specific learning experiences in each of their three years of study. The programme in which they were enrolled took them through three phases in the care of the elderly person: year one, care of the well elderly, year two, care of the ill elderly and year three, care of the critically ill elderly. They found significant positive attitudinal gains in the first year with exposure to the well elderly programme. Based upon this foundation, their experiences in hospital the following year also showed a gain, albeit very modest in comparison. During the final year, there was a slight drop in scores when the students were exposed to critically ill elderly. However, overall, and in keeping with the studies cited above, the attitudes were very positive.

Interestingly, many of their students reported having a strong positive relationship with an older person, their grandparents in particular. Among their conclusions is the point that exposure to the well elderly as patients has lasting value. This point may be significant in the future as nurses with such exposure emerge from Project 2000 programmes.

The experiences of "nurses" with "patients" in the present study would have been with the ill elderly and their attitudes might have been set well before their work with their present patients with venous ulcers began. The implications of negative attitudes in nurses are worrying because as will be seen, it severely detracts from the care they are willing to give. Although the reasons for such attitudes might be very individual, it is interesting to speculate if past exposure had an important part to play or if a lack of appreciation for venous ulceration as a chronic disorder made a significant difference. Perhaps being accustomed to more notably successful patient outcomes from their previous work in acute care settings, they are ill prepared to take realistic views of the situations of patients with long term and incurable conditions. Quite possibly Kelly and May (1982) are correct in their assertion that:

"Nurses symbolically take the role of the patient both to make, and to make sense of, their own role, and it is in so doing that the labeling of patients inevitably takes place. The good patient is one who confirms the role of the nurse; the bad patient denies that legitimation" (p.154).

A patient who fails to recover completely, the person whose wound remains troublesome or who complains of pain might be interpreted by the nurse as a personal failure. It is her job to deliver competent wound care and she has been given the task of caring for patients with leg ulcers by her medical colleague. Her failure to make progress with them might be eased by stereotyping the patients as "difficult" or "old"; certainly blaming the patient for a lack of progress is one very obvious option.

Lubkin(1990) reminds us that we are not uniform as a group in our attitudes towards those with chronic illness:

"Health professionals can view chronicity positively, as a state that can continue to contribute to potential growth of an individual...or negatively, as a state of failure to recover completely" (p. 3).

She elaborates on this point by stating that when negativity is the resulting view it is sometimes based on the "piecemeal exposure" health professionals have to patients. Our contact is brief and episodic and under usual conditions it brings us into contact with people at the worst times in their lives. "To counteract negativity of this kind, the health professional must strive to keep the client's entire life pattern in focus" (Ibid.). This research shows that those health professionals who move beyond the ulcer to the more holistic view of the patient and develop sound relationships with them are more likely to hold positive views of them. Seeing the individual biography and appreciating the interplay of illness, treatment and life as it is normally lived prevents stereotyping.

The findings of this study indicate that the patient who requires professional care because of a venous ulcer has three possible experiences as a result of contact: he may be treated positively or negatively by his nurses or positively by his consultant clinic medical staff. The situation as it unfolds under each of these conditions will next be discussed.

Positive approaches in practice

Being involved in a positive way in the care of a patient with a chronic illness entails an understanding of the nature of chronic illness, an acceptance that home is the main location of care and that the primary focus of the person with the illness is not "merely nor primarily managing the illness, but maintaining the quality of life...despite the illness" (Strauss and Corbin, 1988 p. 47). It further assumes an appreciation of the trajectory of the illness and an acceptance of the fact that it cannot be cured but must be managed to achieve maximum containment. It is the patients and their families who are the key workers involved, arranging their lives in such a way that the required work is carried out so as to minimise disruption to their lives. The work done by health professionals "... is usually very much a part of the overall illness management, but it is only a part" (p. 48). The patient and not the nurse is in control of the pattern of care.

In this study when the focus is the care of a person with a chronic problem, the nurse has a positive attitude towards the patient group and she

acts in a way that might be deemed to be approaching "supportive assistance". Two factors prevent this label from being applied unreservedly: firstly, the approach always begins as a medically modelled one with the nursing management only emerging over time and, secondly, and more importantly, the patients are not returned to their rightful navigating position unless wound healing occurs.

This style of nursing is found in both District Nursing and in Practice Nursing but it is more commonly seen in Practice Nursing because in that context one nurse has the ongoing nursing management of a patient's care. In District Nursing it is more often found in association with those District Nurses who are more senior. This association needs to be seen in the overall arrangement of nursing care on the district where a specific nurse has charge of the care for her patients but on her days off and during her holidays, for example, other nurses from the team to take over that care. If a nurse is junior, leaving her knowledge base aside, her decisions regarding care are more likely to be overturned if they do not fit into the expectations of her more senior team members. A more senior District Nurse is generally protected from this interference and her standing in her professional group insulates her patient.

In this situation the patients tend to flourish as individuals and the relationships between the nurse and the patient are very positive. Patients have the opportunity to take a more active role in decision making and it is easier for them to discuss issues of personal importance with their nurses. The following anecdote typifies the nature of the relationship that can be developed:

"Mrs. X was wanting to go on holiday to Austria so we talked about that. She was concerned about her leg ulcer so we discussed whether or not she was going to live her life to the best of her ability with the leg ulcer, or was she going to let her leg ulcer keep her at home? But, she was going to take the responsibility that when she got back home her leg ulcer would have probably deteriorated somewhat because she was going to have a 24 hour coach journey each way with her leg dependent. We talked about it and she decided to go. I said: 'that's fair enough, just remember to keep your leg up when you can, bandage it'. We talked of things she could do to perhaps keep her ulcer from deteriorating. "

The ulcer did deteriorate over the holiday period but the nurse, with equanimity, added that "we" had the ulcer back under control in a couple of weeks: "And she had had a lovely holiday".

The nurses' beliefs about the central position of the patient to the process of care could be summarised by the nurse who stated:

"I think people have the right to be their own advocates and decide their own way of life. It's not up to us to tell them how to lead their lives so that their ulcers will heal up"

Patients cared for by nurses with this orientation and attitude are far more knowledgeable about their care although not about their condition. It is common to find nurses in this category who are keen to share decision making about treatment options and who are also enthusiastic in instructing their patients about life style factors that might assist in the resolution of their wounds and the containment of their condition. However, teaching about the underlying cause is rarely shared. By monitoring the responses of the patient to the instructions, the nurse can gain feedback about the nature of the underlying pathology. Normally, the patients recount that they put their compression hosiery or tubigrip bandages on before getting up in the morning, rest their legs in an elevated position whenever possible, are careful to protect their lower legs from any irritation or chaffing from boots. They know their part in achieving healing but none understands the rationale for their actions.

However, they are not slavish in following the health instructions they have been given. Table 8 illustrates the nature of the patients actions in response to their ability to participate in their care. Those in this section could be termed "collaborators" or "adjusters". One lady recounted that because she was going to a wedding she left her usual compression bandage off and wore support tights instead over her dressing for the afternoon and another remarked that she usually wore her compression bandage but she was "vain" and didn't like to come to town wearing it so for the occasion she had applied a much lighter and less conspicuous dressing. Alterations to the recommended practices are made with knowledge; "noncompliance" is a matter of an

Compliance

	+	-
+ Participation	COLLABORATORS negotiated decisions informed discussions	ADJUSTERS occasional modifications with understanding
-	BARGAIN HUNTERS enduring treatment regimen	RESISTORS adjustments made to suit biography and comfort

Table 8 Patients actions in response to opportunities to participate in care

occasional deviation and is handled with personal understanding. These patients collaborate in their care and understand the regimen; when they choose to deviate, that is, to "adjust" their care, they do so temporarily and with knowledge.

In this positive approach to care the nurse is routinely more knowledgeable about ulcer management than her negatively disposed counterpart and she is always a realist. Lesser forms of compression are applied not because the nurses do not appreciate the role of compression in dealing with venous ulcers but because they accept two additional facts of living with an ulcer: a) most bandages over time and with normal mobility end up slipping and this negates their purpose and b) some compression is better than none and with less compression the patient would be more comfortable and more compliant. As one Practice Nurse aid:

"With some other bandages, the blue line and the elastocrepe, you get more compression—at first—but no matter what you do they are always sliding down and a leg not to be bandaged correctly may as well not be bandaged at all. Whereas with the tubigrip at least you've got some support there. Sometimes I'll use two instead of one depending upon how comfortable they are you see. . . I think if you put something on a patient that they feel comfortable with, they are more likely to keep it in place; if a dressing is comfortable you're less likely to disturb it."

Patients who are able to take over aspects of their own care are encouraged to do so but they never achieve their navigational position unless their ulcers heal. It is the norm to find nurses in this category instructing their patients on "in between visit" ulcer care but the overall control is retained by the nurse. The patients are assessed very individually and those who have limited mobility or sight or some other limiting factor have all their ulcer dressings done by the nurse. Sometimes the patients might not want the involvement at first, perhaps because they are afraid of making a mistake, causing the wound to become infected, or because they find the sight of the ulcer unpleasant. The nurse works with her individual patient and encourages participation in care when appropriate. In the case of negative emotional reactions to the actual ulcer, the gentle coaxing and positive approach of the nurse seem to assist the patient in accepting it as, perhaps a problem, but no

longer as something disgusting about their bodies. Negotiation is the norm in this approach. One patient mentioned that initially she attended the surgery three times a week and after a time she felt she could manage the dressings herself:

"I said to her: 'I could manage if you would just tell me what to do' I'd taken first aid years ago and I did home nursing years ago--my mother was a nurse, but of course she wasn't alive when I had this one. And I said if I got into difficulty I could always come back and she said: 'Are you sure?' and I said 'yes' and she found out I could manage and I wasn't making any errors really, and if I got into any difficulty I used to say 'I've come up because I'm not sure about something and I'd like you to look at it and see what you think' And she is quite happy and the doctor's happy and if they are happy, well, of course it's that sort of thing. She gives me a supply of things and I get on with it."

This sounds like a solo navigator but in fact at the time of interview her nurse indicated that she was seeing her at the surgery once every other week "just to keep an eye on it".

Occasionally there is a problem with compliance when the condition of the leg and ulcer has changed or when other things in the patients life add to the burden of living with a chronic problem. However, the nurse's response is typically:

"On the odd occasion when the patient just cannot manage, then usually just talking, reasoning, debating, negotiating--we come to some sort of a compromise"

It is, after all, the patient who is the centre of such care and the nurses realise that the patient knows what they are able to manage: "I'm not the one with the bandage on my leg!" one District Nurse concluded.

Of all the patients with leg ulcers, these are the ones who participate the most in their care. However, this participation is very limited: they might be asked how they think their wounds are healing with various dressings, or asked if they would like to try another, or they might at best be empowered to carry out in between visit care. However, they feel that they are consulted and visits are enjoyed by both and over time they come to know each other quite well. Patients remark that they can chat to their nurses, swap a recipe or a story with

them and they relate to them not as if they are in a situation of unequal power but almost as friends:

"I said : 'Brenda(the nurse), I can't go to church in that thing' (support bandage) and she said: 'Well will you promise to put it on again when you get home?' I said: 'I promise faithfully'"(laughing)

Of all the nurses, these are the ones who expressed most satisfaction with their dealings with patients with leg ulcers. The examination of the nurse-patient relationship by Ramos (1992, p. 503) found that this type of deeper bonding between patient and nurse where there was a "reciprocal relationship with resolved control issues" is the most satisfying to the nurses. These nurses know their patients well as people and can see the world through their eyes to some extent: at least they take the trouble to try. Their nursing care as a result is more tailored to their patients and their approaches more individual. Ramos found, as this study also shows, that this level of relationship with patients is not particularly common: only approximately one third of her sample of nurses indicated that they had ever experienced it.

Negative approaches

Not all nurses deal with their patients in a generally positive way and it is not uncommon to find nurses who recognise that the patient with a leg ulcer is an older person with whom they prefer not to work. Noncompliance is a problem in the patients in this group. The nurses, however, so expect compliance from this group that they feel justified in berating the patients for assuming any degree of navigational function as is clearly seen in the following quotation:

"Once you get the patient sorted out with what I want to put on--it's compliance! People just won't go to bed. They'll sit up all night and they won't raise their legs and they won't do all sorts of things that they should do. AND they won't leave things alone; they are quite happy to leave the chiropodists dressing alone for three weeks but the District Nurse's dressing? If they want to have a look, they'll have a look the next day! That's probably the most frustrating thing for me."

This approach is nurse centred and very much medically modelled: the nurse is seen as the expert who will decide the appropriate treatment. There is a definite bias in this category against the elderly; the younger patients with leg ulcers are not spoken of in the same way. In the case of a younger person, the nurse might describe how she works around the person's lifestyle and obtains a history from the patient, whereas in the case of the older person, more control is exerted and negotiation is not used to the same extent. The younger person is instructed in dressing the ulcer and more or less manages without the nurse. The approach to the elderly however, verges on the combative.

"Sometimes it's sheer cussedness. The "I know better; I've had this leg ulcer all these years" and I say: Well, that's fine! But if you'd just like to give this dressing a try—you can do it yourself! If you don't want to do it yourself I'll pop in once a week or twice a week –just to keep an eye on it and see how you are doing."

The mutual respect prevalent in the previous category is absent and the patient is mistrusted in a variety of ways. Because he was older, the history he could give is assumed to be "a bit erratic so I find out more about the person before I go in". There is much in common here with the situation of the stigmatised individual. Stigma "is really a special kind of relationship between attribute and stereotype" (Goffman 1963, p.14) and it is in dealing with the older individual as if he were the negative stereotype that makes him stigmatised in this situation. His age and his venous ulcer can both be used to characterise him as a less than "normal" person and as: "We tend to impute a wide range of imperfections on the basis of the original one" we can justify the way we treat him.(p.16) As Goffman stated (1963,p.19):

"Those who have dealings with him fail to accord him the respect and regard which the un-contaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving"

When the rate of healing is not as expected, direct communication with the patient is not the first thought:

"The SEN asked if I could get Mrs. X some stronger water tablets. Well, I said: 'Just surreptitiously count her tablets and see if she is taking them'"

The attitudes expressed by this group of nurses are worrying particularly as we live in a society in which the number of elders is increasing and, with age comes an increased need, overall, for nursing and medical care. A number of researchers have examined ageism in health care in search of key variables associated with it but the results are largely equivocal. Pursey and Luker(1995, p.549) suggest that the majority of the studies confuse the "concepts of attitude, belief and behaviour" and in their study of a convenience sample of health visitors, health visitor students and practice nurses they conclude that nurses can hold negative feelings about working with older people in the structural context of their work and still have "more positive feelings about individual older people with whom they work" (p.553). However, in the present study, the attitudes expressed are linked not simply to patients in general but to specific individuals and whereas it might be more comfortable for nurses to take the view that their stereotypical views are not translated into the care they deliver, this judgement is not supported.

When invited to describe their experiences in caring for patients with leg ulcers the nurses with this negative attitude routinely responded by labelling their patients in terms of their pathology and even as inanimate objects. In the first quotation, from a nurse who describes her earliest experiences with patients who had leg ulcers, it is also important to note the task oriented focus:

" I started with leg ulcers in outpatients as a cadet before I started training...we were allowed to do dressings and allowed to do all sorts of things. And then --from then I didn't have a lot of experience throughout my training except for the fact that we had six skin beds on the ward I staffed on and some of those were leg ulcers."

Another nurse remarked that she had not come across "leg ulcers" (note, not "patients with leg ulcers"):

"The first time really I suppose I was aware of the problem was when I qualified and worked at X hospital; we got an awful lot of leg ulcers in at casualty for treatment. My memory of all of them--they were huge, fat,

old ladies who could hardly walk and I don't remember questioning why I was doing it (dressing the patient's leg ulcers). I just took the dressing off and put another one back on"

That elders feel an ageist bias from society in general is indicated by a small scale study of elders in a day centre and a shopping centre (Fuller, 1995, p. 29). The majority (75% of a sample of sixteen) felt that they were spoken to differently in their retirement years than they had been when younger and "The main difference was described as being a lack of respect" (p. 30) yet the majority seemed to have accepted this situation as inevitable. The patients might not feel able to respond to their treatment in some cases. Many are not at all satisfied with the care they receive but do not feel that they can complain; their views of "grounded caring" will be discussed in chapter 6.

Forcing resistance upon the patient: resistors and bargain hunters

Linked with the ageist bias is the approach to the patients that insures that there is limited communication. Hewison (1995) conducted a non-participant observational study of interaction between nurses and patients in a ward caring for elders. The findings indicate that "most of the interactions were brief, superficial and related to tasks" (p. 32). The most common way of nurses exerting control over their patients is through "controlling the agenda" in which "routine communication which indicated and reinforced the action the patient should take" is used. This pattern is noted in the nurses comments of their interactions with patients in this study. Participation is not encouraged and patient contributions are barely tolerated. Lacking the opportunity to take the central role in decision making and having been marginalised by the nurse navigator, these patients could respond in only one of two ways: through becoming "bargain hunters" and trying to strike an occasional deal with their nurses to obtain more acceptable care, or by becoming "resistors" who simply altered treatment once the nurse was gone from their homes.

Participation in care depends on a number of factors and all of them are missing in this category: sharing a knowledge base, attunement one to the other, the acceptance that one can contribute worthily to decisions and a feeling that in the interaction one's identity is not under threat (Ashworth et. al

1992 p. 1430). Information was found to be given in this study only under certain conditions:: "if teaching them will help to heal the ulcer", "if they are really interested," and "if they have got the intelligence to understand". As one nurse said:

"I feel they must know about compliance basically—what to do, what not to do etc. and as far as if they respond to that I am quite happy—about resting and exercising and various aspects of it."

Lifestyle in the older person in this group is tackled in a fairly bombastic way:

"Don't make an invalid of yourself! It hurts, sure, but not as bad as an arterial ulcer. It hurts, but they are not agonising!"

" I think the important thing for the patient is not to let it alter their quality of life because a lot of people do. They decide they're ill and sit in the house all day. The reason they've got them in the first place is they sit there and stagnate"

"Yes it can dominate their lives—particularly the long term ones. Yes, BUT they were the ones that wouldn't go out, didn't go out for long periods of time you know—the housebound, the homebound and I think because of their leg ulcer they didn't want to go out. It was the embarrassment—the look. I think they really didn't want to help themselves."

There is no appreciation of the central position of the patient in this approach. The position taken by this group of nurses is rationalised in an attempt to make it appear acceptable and even reasonable:

"My experience from the patient's point of view is that all the patient wants is for you to heal the leg ulcer up. A lot of old ladies don't like to take on board that part of the treatment—what they've got to do. They want you—I find this with the older generation in so many things—they are not used to empowerment. Um, all right they don't necessarily abuse the NHS—they have been brought up to believe that the doctor and the nurse—they will get you better and I think the generation we are dealing with now—well, empowerment is not a word they want to hear about—they don't want to take the responsibility"

The study of Waterworth and Luker (1990) would seem to support the above nurse's view that people might not want to share power or decision

making with their professional carers. However, it is important to reassess their conclusion because it was reached from interviewing twelve patients who were on hospital wards for unknown medical conditions. One patient mentioned that, whereas, there was no force to do so, he obeyed the rules of the ward because he thought they were reasonable. He commented that he would expect the nurses to obey the rules of his "jurisdiction" if they were ever within it. Another mentioned that she would not consider complaining of anything because in the ward she was "at the mercy of whoever". The patients interviewed by them were perhaps "reluctant collaborators" not because they did not wish the situation to be otherwise but because they were very aware of the imbalance in power within it.

The comment of one nurse in the present study who said: "The older they are, the worse they are!" perhaps summarises the attitudes of the nurses in this category. Given this viewpoint, it would be an unusual patient who would be able to regain a central position in care and, in this situation, force his nurse into a role of "supportive assistance" which clearly is not one she assumes as a matter of course.

Levels of Knowledge

Nurses with a more negative approach indicate poorer levels of professional knowledge of the pathology and management of patients with leg ulceration than those in the positive group. In fact, major inaccuracies and errors are commonly demonstrated during interview. This was surprising because one would have thought that a nurse who did not like dealing with a patient would ensure that her knowledge base was good if only to speed the patient's passage from her care. However, it would appear that the negative stereotyping done by this group leads to or stems from a disinterest in their care. Although it is not uncommon to find in the literature that nurses are ill prepared for their role in wound care, the relationship of a lack of knowledge related to a particular aspect of care and a particular group has not been explored. In this study stronger cleansing agents tended to be used by nurses in this group and similarly, dressing choices more often included those considered to be "dry dressings", the tulle specifically. These are often used

despite a lack of rationale for their ongoing application. Comments such as : "I know it is not approved of anymore but I....." were commoner in this group. There is an awareness of new knowledge but not always an acceptance of it.

The consultant clinic: positive approaches through medical care

A person can be referred to the consultant clinic for a number of reasons. Most often the long duration coupled with deterioration initiate the referral. However, occasionally a District Nurse may ask for an examination by a consultant to give guidance to her treatment. She assumes in referring her patient to the hospital consultant that a full examination will be carried out and will include a doppler assessment. This assumption is largely unfounded and patients, although "seen" by the consultant, are not examined at all beyond the visual inspection of the wound. At best, they have this superficial assessment coupled with what could be described as "doppler search" for the dorsalis pedis or posterior tibialis pulse. That is, the ankle/brachial index is not always done but rather, the mere presence of the pulse is determined by using the doppler. The adequacy of this approach might be compared with listening for a heart beat and on finding it, attributing a normal blood pressure as a result. No further examinations are routinely undertaken. However, given these limitations, the consultant is then in control of the care which emphasises patient comfort as well as wound healing. The treatment approach tends to be aggressive in terms of aiming to heal the ulcer if at all possible. Stronger systems of compression are applied but if the patient requires the short or longer term use of stronger analgesics to cope with treatment, then these are available: decisions that the general practitioner would not even consider become acceptable when they originate with the consultant. Therefore, the patient with extensive and painful ulceration may even be prescribed morphine sulfate, for example.

There is an appreciation on the part of the consultant and registrar that they are assuming the care of the patient often after an extensive period of treatment in the community. Therefore the patient is considered to be knowledgeable about what suits him in terms of dressings and bandages and he is consulted on these matters. As would be expected in this context, the

patient is routinely asked for his opinion of how the treatment is working and what he thinks of progress.

"They will ask me how I am feeling and say: 'Well that looks a bit more dried up today' and if I tell them that the stuff we're using is doing good, they let you come home using the stuff"

"Well, the last time Doctor....(registrar) said: 'I think I will put you back on the tea bags(this is a colloquial term for one particular dressing that looks similar to a tea bag). What do you think?' Well I said : 'You're the consultant, not me! But as far as I'm concerned, it's doing well. He said 'What did the nurse think?' and I said 'About the same as me--she wouldn't change it'. He said: 'Right, we'll carry on then"

Question: "What part would you say that you play in deciding what happens to you and your legs?"

Answer: "Well, I'd say a big part because they always--what I like about it is--they always tell you what it's like and if it has improved. And if it hasn't improved they say what they think is wrong--and they are always willing to try something if you've got a suggestion. The District Nurse will do that too but she can only do it with dermatology say so, you see. But they are always willing to listen and they always listen to what you've to say and what you think."

These patients are the most knowledgeable about treatment regimens having discussed them at the clinic and they also become accustomed to asking for advice when necessary. They develop relationships with the clinic staff and ask questions of those they know and with whom they feel a rapport. This is particularly helpful to those who have a number of District Nurses giving them care. The additional benefit of the clinic setting is the opportunity provided to have a cup of tea and a chat after treatments have been done, either while waiting for transport home, or just as a social option. This context provides opportunities to learn more about ones reference group and extra time to talk to the staff.

The District Nurses, to whose care these patients are returned in the intervals between visits have limited control over the treatment of the leg ulcer itself. Any alterations have first to be discussed with the consultant clinic staff. The healing rates of the consultant clinic attenders are not impressive: patients continue to attend for months and in some cases, years. However, the range of patient options increases with referral and pinch grafts, full skin grafting,

admission for bed rest and ongoing treatment are all available to these patients. The fact that the decisions are emanating from the consultant clinic makes the District Nurses' relationship with these patients far more normal: she is no longer playing a medical role but rather is carrying out the prescriptions of a senior doctor. When questions arise from the patient, the nurse can act as advocate and intermediary in between visits and obtain information for her patient: the arrangement of care makes her work far more satisfying.

The nurses who worked in the consultant clinic are however, the least knowledgeable in terms of leg ulceration of all nurses interviewed or observed. The alliance with the medical specialists allows them to simply carry out the doctor's orders without the background information that is necessary for them in terms of accountability.

Negative responses from the consultant clinic nursing staff

Infrequently a patient will have a problem with a nurse in the consultant clinic. Although normally a place where very positive relationships are developed it is possible for personality clashes and conflict to occur. The consultant does not see every patient on each visit and although the registrar inspects each wound and has a word with each patient, it is usually not a lengthy interaction. This brief encounter provides the patient with an opportunity to seek a change in the treatment with which the nurse might be quite happy to continue. The conversations have to be managed carefully by the patient because the nurse is always present. The following quotation is typical of the polished approach to conflict management:

Patient: "Well, nurse thinks it's doing fine but I think we should go back to the other dressing—the tea bags—it was much more comfortable with those one. What do you think?"

Very occasionally a patient is not able to challenge the treatment of the nurse directly or in this circumspect way and becomes emotionally upset in the clinic. The onset of tears might not soften the nurse's approach but the consultant or registrar is then always called to see the patient and approaches these patients with kindness and understanding. The composure and comfort

work are routinely performed by the doctors in these situations. More often than not the problem stated is with the pain the treatment is causing and in these cases the bargain is usually struck that a prescription for stronger analgesia will be arranged in return for compliance.

Summary

The attitudes and professional knowledge of the health professionals have a pronounced impact on the lives of the patients in their care. Much can be done to ameliorate the situation of patients with venous ulcers. They have a chronic condition that demands long term commitment, not simply from them but also from their nursing and medical supporters if positive outcomes are to be realised. Regardless of their personal attitudes, the nurses are faced with complex symptoms and signs to interpret and in the following two sections the reciprocal impact of the condition and its management on the lives of the patients will be explored. In the first section the main presenting symptom of pain is discussed in considerable detail. There follows an exploration of the other significant ways in which the condition, its management and biography interact to make normalisation problematic.

Section F Reciprocal Impact

Introduction

"Reciprocal impact is a very important concept in the trajectory framework. It is the consequence component. Its purpose is to sensitise us to the complexity of management and the potential compounding of problems that can occur due to the interaction between illness, biography, and everyday activities" (Corbin and Strauss, 1992, p. 19). The interplay of the illness and its management on the lives of the sufferers of venous ulcers creates a cycle of suffering for most patients, particularly in the early days of *professional navigating*. It is a cycle that is known and recognised on an intellectual level by the nurses but the depth of the personal disruption to the patients and its significance to them has been essentially ignored. Any nurse who works with patients with this condition will easily provide a list of ways in which it disrupts life; what almost all fail to relate are the ways in which their commonly employed professional practices and approaches add to the problems and increase the suffering of their patients.

The reciprocal impact of venous ulceration and its management has been essentially a hidden phenomenon with few nurses penetrating through to this level of meaning. The patients' anxieties, their problems with pain and with the everyday presentation of themselves are virtually absent from the professional literature. As they progress further into care administered by health professionals, these patients develop their own views of how they would alter their treatment if they could and in fact their views allowed the researcher to discover what "grounded caring" would equate to for them as a group. Their willingness to share their feelings and thoughts allowed a full picture of their concerns and views to be produced. The reciprocal impact relating to pain will be dealt with in this section followed by a discussion of the reciprocal impact of the other significant symptoms and their management. Grounded caring will be discussed in depth in the concluding chapter.

Part a) Pain and professional deafness

Professional deafness: a problem of focus

Those who enter the role of patients do so because they want help with their non-healing, deteriorating and painful wounds. Their professional carers want to help and appear to have the same focus. However, despite the apparent agreement in terms of goals, the patients soon find that their priorities are not shared by their nurses. The conflict of focus is represented below in Table 9:

	<u>PATIENT</u>	<u>NURSE</u>
<u>FOCUS</u>	PAIN	ULCER
	BIOGRAPHY	DIAGNOSIS

Table 9 Conflict of focus

The patients most often want relief from their pain, which at the point of consultation has become disruptive to their lives; the nurses view their complaints of pain as being of diagnostic or of clinical significance but, in general, do not deal with the experience of pain other than as it affects their care of the ulcer site. For the patients, the important presenting symptom is pain; to the nurse, it is the ulcer. Over time, the focus of the nurse tends to change if the patient and nurse are able to establish a relationship in which the persons emerge from the roles. However, by that time, the patient has usually suffered considerably and it is perhaps surprising that it is possible to form relationships akin to friendships in these cases.

The situation of conflicting focus is a common one particularly in chronic illnesses. Thorne and Robinson(1988a) examined health care relationships in a number of chronic illness contexts and from qualitative studies using

grounded theory methods, they were able to discover the evolving phases within them. They found that patients and their families move through three stages: naive trusting, disenchantment and finally guarded alliance(p.296). The naive trusting stage occurs early in the experience of chronic illness. In this phase the patients and their families assume that their perspective is shared by the professionals who care for them and they wait passively fully expecting that there will be respect for them as care providers, and acknowledgment and inclusion of them in collaborative and cooperative decision making. The next phase of disenchantment is "characterized by dissatisfaction with care, frustration and fear" (p.297). At this point the patient and family have come to realise that the process of care has been taken from them: it has moved into professional hands. They cannot reach "effective and satisfying involvement in care" because they have difficulty in obtaining information. Under these circumstances it is not unusual for the relationship with the health professionals to become "adversarial" but there is a recognition also that this is perhaps counterproductive: they need the professionals and if they alienate them, the results might be worse for the patient:

"If they remained passive, their experiences had taught them that the sick person might suffer a negative experience; if they actively sought involvement, particularly in decision making, the sick member might suffer from the diminished 'goodwill' of the health professionals" (Ibid.).

The chronic nature of their problems however, makes them come to an accommodation: they have to listen to and trust these professionals. This need leads to "guarded alliance" which is a form of reconstructed trust. It is no longer naive and it acknowledges: "both the strengths and limitations of specific professional health care providers" and it is not an overall trust in the system(p.298). The participants actively seek information, admitting differences in perspective and promoting negotiation. But at the same time they remain vigilant and ready to act as advocates for the most positive experiences available. There are definite attempts to develop closer relationships, to gain understanding, to "humanize their relationships with health care professionals" (Ibid.) and this strategy is seen in gift giving and the increased interest in the

health professional as a person. In fact the individual and family learn to limit their complaints and concerns so as to manage the relationship to their best advantage. It is of considerable interest in relation to this study that Thorne and Robinson found that patients and their families judge competence not by technical merit but in terms of "human qualities", an area they feel able to assess with confidence. When the patients express anger against their carers and care, it is not the treatment that is found to be problematic but the manner of the nurse. However, the patients in this study as in Thorne and Robinson's, are caught in an impossible situation because they recognise that unless they gain the personal interest of a health care provider, or at least do not antagonise her, then their situation will suffer.

The following section will focus, firstly, on the presenting symptom of pain as it is expected to occur in the *patient with a venous ulcer*. The nursing approaches to its management will then be discussed before focusing attention on the actual experiences of the patients. The early phase of acute pain will be seen to lead into a prolonged period characterised by chronic endurance on the part of the patients; at no point will pain be seen to be accurately assessed nor adequately dealt with as a matter of routine. The experiences of the patients will be seen to contrast starkly with the priorities chosen by their nurses. These patients found, as did those interviewed by Thorne and Robinson (1988 b, 783):

"that health care professionals did not generally understand or even care about the patient's perspective of his own best interest, rather, the professionals based decisions upon a set of values distinct from and often contradictory to the patient's own values."

Pain : the anticipated presentation

Nurses and doctors simply do not expect venous ulcers to be particularly painful and numerous authors over the years have confirmed them in their belief that pain is associated only with arterial ulcers or with venous ulcers complicated by other factors. According to the majority of writers, venous ulcers "are not usually painful" (Buxton, 1987, p.1543) and "...are only painful if associated with bacterial infection, cellulitis and oedema" (Cornwall, 1986, p.203). So widespread is the belief in the literature that venous ulcers are not

painful that Bennett and her colleagues (1985) felt confident in using the absence of pain as a factor that could be used to differentiate between venous and other ulcer types. To select patients with venous ulcers, they state: "the criteria that were used were those that were consistent with the literature and related to absence of pain, site, oedema, exudate and pigmentation"(p.38).

There is sometimes a recognition that venous ulcers are less than comfortable but the amount of pain that the patient might experience is often underrated. Browse, Burnand and Thomas (1988,p.379) mention that *ulcers* are often painful but they clearly differentiate between the two most common types and emphasise the differences in terms of the degree of pain:

"Pain made worse by elevation is often a feature of ischaemic ulceration, whereas the discomfort of venous disease is almost always relieved by elevation."

Note here, how "pain" has become "discomfort" and the more distressing symptom has been attributed to arterial disease. Similarly, it is important to note the simple measure said to relieve it: elevation is all that is required. This is very much in keeping with Porter (1979) who recognised that there could be a problem relating to comfort in these patients but, as a rule, it was a minor one: "Stasis ulcers are not usually associated with significant pain, although aching is frequent"(p.39).

The anticipated presentation of signs and symptoms is an integral part of the assessment routine and was often mentioned by the nurses interviewed for this study. As one practice nurse said:

"They get a tingling sensation in the actual ulcer bed itself and that's usually when they need changing or as they are being changed. But once--generally speaking, once a venous ulcer is dressed and settled, it is usually fairly comfortable. And, give or take the odd Paracetamol, they haven't needed a lot of analgesia for pain relief. It seems to be the arterial ulcers that are the little beggars; they get to bed and I've known people to be crying with arterial ulcers...But people with venous ulcers, they don't seem to have the amount of pain you would associate with such horrific looking things sometimes. Mrs. X, she had hers twenty years and it was as big as a saucer--down to the bone! And it never gave her a minute's trouble."

A District Nurse who stated that she assessed her patients for pain said:

With venous ulcers I find very few have pain unless it is oedematous or infected. If they have a venous ulcer and they say: 'Oh, my leg has been really quite sore', I will look very closely at it and probably take a wound swab and say: 'We'll catch this before it gets going.'

Pain is also expected to be associated with prolonged standing through an increase in oedema and nurses would be familiar with the description from a patient that follows:

"It hurts when you stand for a long time; it nearly sends you crackers. But, as soon as you can get anywhere—I have sat with my foot up even on the fireplace—the higher you can get it, the better and gradually it eases down."

The recent literature

During the last few years there have been indications in the literature that pain is indeed part of the presentation of venous ulceration but these references seem to have been overshadowed by the wealth of material indicating otherwise. The medical literature began to recognise pain in these situations first and this awareness has since been followed by some recent nursing research findings. Gross and his colleagues (1993,p.271) for example, in describing the clinical syndrome "consistent with that classically seen in venous leg ulceration" includes the finding that "88% had leg or ulcer pain." Burton (1993, p.316) states that pain was not particularly useful in diagnosis and that "venous ulcers may be just as painful as arterial ulcers." The degree of pain that might be present was clearly stated by Bliss (1990,p.186):

"The ulcers themselves often become acutely painful when the legs are first elevated, probably due to prostaglandin synthesis resulting from a restoration of the blood supply, so that regular analgesics, including morphine, may be necessary for the first few days."

The nursing studies that recognise pain as a feature of venous ulceration consist of Walshe(1995) and Hamer et al.(1994). Walshe (p.1095) conducted interviews with thirteen patients with active venous ulceration and found that

pain was “the overwhelming feature of the experience of leg ulceration” and this confirms the findings of Hamer and colleagues (1994, p.100) that 37.5% of their sample of 88 patients reported that pain was the “worst thing” about having a leg ulcer. All of these references are relatively recent. Perhaps now that it has entered the professional literature it will be attended to but it is indeed very worrying that the degree of pain that these patients experience has been hitherto unnoticed.

Pain: usual management

If pain is found to be a feature in a patient with a venous ulcer, an explanation is sought by looking for signs of oedema, infection or arterial involvement. It is usually handled by direct treatment of the recognised cause: infection is treated with antibiotics and oedema by compression unless the ankle/brachial index indicates significant arterial compromise would preclude this approach. It is very unusual to find pain treated as a personal experience or to find effective analgesia prescribed. The management decisions taken presume that the patient's pain is ulcer related and the interventions chosen reflect this assumption. Unfortunately, the responses made, although logical and research based, are also incomplete and almost invariably ineffective, leaving the patient in considerable pain particularly in the early stages of ulceration. The three common approaches to pain management are: dealing with infection, choosing dressings known to be associated with pain reduction and compression therapy to reduce the oedema. Each of these strategies will be discussed before turning attention to the actual experiences of the patients.

a) Dealing with infection

It is important not to overlook infection because it delays or prevents wound healing. Robson (1988) and Alvarez (1989) note that infection disrupts the healing process by prolonging the inflammatory phase, causing further tissue damage, delaying collagen synthesis and preventing epithelialisation. If a wound is suspected of being infected, it is routinely swabbed by the nurse and cultured in order to establish the appropriate antibiotic for the offending organisms. It should be noted however, that it is not

always possible, visually, to assess a wound for the presence of infection. Practitioners, either medical or nursing, generally rely on the presence of the obvious signs of infection: erythema, oedema, induration, purulent discharge, foul smell, and pain but these are not always reliable indicators. In the case of the patient with a venous ulcer, oedema with accompanying hardness of the tissues and pain are generally well demonstrated but the professionals expect oedema to produce induration and some discomfort. If the remaining signs of infection are not present, then, any pain the patient describes will be discounted because, to the professional, the pain is usually only attributed to infection or oedema. That the nurses might be failing to recognise infection and thereby further delaying pain reduction is quite possible.

Robson (1988) found that wounds could have silent infections. He noted that if wounds were colonised with bacteria above 100,000 organisms per ml., they exhibited delayed healing. He assessed the ability of doctors to recognise these cases of silent infection and found that 34% of wounds deemed to be clinically free of infection were in fact colonised above that level. He has stated that the only exception to his definition of wound infection occurs in the case of B-haemolytic streptococcus which can interfere with healing at counts below the 100,000/ml. level. This particular organism has been thought to be an uncommon problem in leg ulcers but Schriabman(1990, p. 123-124) found that 18.8% of the "bacterial isolates from 91 legs of patients with leg ulcers swabbed routinely" were of b-haemolytic streptococcus. He indicated that unless a specific culture medium is used in bacteriological tests, then it will not be found. As this organism is known to cause considerable skin destruction, Schriabman urges its identification and eradication by the simple administration of such common antibiotics as penicillin V or erythromycin. It is interesting to consider what part unrecognised infection with B-haemolytic streptococcus might cause. If the wound appears infected and a swab is taken without employing a specific culture medium, the resulting bacteriological report might indicate that other organisms were responsible for the infection. The core problem, thus being missed or treated indirectly by a reduction in the general bacterial loading at the wound site, would not bring about the anticipated relief of pain. The usual practice of swabbing ulcer sites does not include the use a

medium specifically designed to support this organism and therefore may be contributing to the prolongation of pain and wound healing.

However, there are those who disagree with the views of Schriabman and Robson and in general it can be said that the administration of systemic antibiotics in the treatment of patients with venous leg ulcers remains controversial unless clinical signs of infection are present. The three main opponents will next be presented. Alinovi and his colleagues (1986) studied the bacterial flora in the ulcers of forty seven patients. Dividing the group into two groups, the team administered oral antibiotics specific to the organisms found on culture to the experimental group. Both groups received the same cleansing and dressing regimen which included compression bandaging. They were able to demonstrate quite clearly that wounds with beta haemolytic streptococci healed completely without antibiotic administration. Their overall findings indicate that the rates of healing in either group are not statistically different from each other but they found greater rates of healing in wounds that had negative post treatment bacterial cultures. They conclude:

"The disappearance of bacterial flora could have played an important role in promoting a higher healing rate, or, alternatively, the disappearance of bacteria could have been a secondary phenomenon occurring in cases with the greatest haemodynamic and environmental improvements induced by the compressive bandaging. Since healing rates have not been influenced by antimicrobial therapy, the latter explanation appears to be more likely"(p.191).

These findings are congruent with those of Erikson and his colleagues (1984, p.175-180) who found that patients with and without beta-haemolytic streptococcus in their venous ulcers healed during their clinical trials. Their team used different non antibiotic wound care products and concluded that their patients(N=53) kept the bacterial flora they began the study with and that "Healing was found to be independent of the bacteria present in the ulcers"(180). They further advise against the topical treatment of leg ulcers with antibiotics because of the dangers of producing allergic reactions and antibiotic resistance. Similar to the conclusion of Alinovi and colleagues cited above, they state that "the most important procedure for healing appears to be

elimination of the oedema and promotion of blood circulation" (Ibid.). Perhaps the disordered microcirculation and not infection is the cause, at least for some patients, of the pain they experience. If, by compression, an improvement is brought about in the microcirculation which allows the removal of toxic metabolites and a reduction of inflammatory stimuli, then pain would logically be expected to decrease. This response would be in keeping with the assumptions proposed in the white cell trapping theory previously presented (Thomas et. al. 1988, p.1695).

Gilchrist and Reed (1988 p. 83-87) studied the bacterial flora in twenty chronic venous ulcers in eighteen patients and found that, as in Erikson's study, there was very little change in the bacterial flora present on the pre and post treatment swabs. The average rate of healing over that period was 58.3%, which would not be anticipated if the bacteria were problematic to the wound site and host. Two of the ulcers grew b-haemolytic streptococcus and as these patients are not singled out for special mention, the reader is led to assume that, under occlusive dressings, there is no significant difference in patient outcomes.

Whether silent infection or subclinical infection is the key problem implicated in the maintenance of chronic venous ulcers and responsible for the period of *acute pain noted in the initial phase* of medical and nurse shaping is not known. There is indeed a delicate balance between host and microorganism and it may be that the antibiotics, when administered, affect, not the ulcer, but the person in some other way, perhaps resolving a subclinical infection and improving the overall condition of the patient. At this point it must be said that the answer is not known. Obviously, finding the specific cause would permit targeted treatment and thereby a reduction in the pain. There may however, be indirect evidence that "silent infection" is a significant cause of pain and this is discussed below.

b) Dressing choices

The nurses in this study made specific choices regarding the dressings they wanted the doctor to prescribe and many of them indicate that their choice is based on evidence that they reduced pain. The choices made are not always

based upon research findings but contrary to the findings of Flanagan (1992, p.77), who, in her study of twenty four hospital nurses, found considerable evidence of ritualistic practice, few nurses in this study were found to be making choices that are not supported by current research evidence.

Many of the nurses interviewed in the course of this study remark that they choose occlusive dressings because they are more comfortable and are associated with faster healing and with less pain. Similarly the popularity of an iodine based dressing is supported by comments that these reduce wound pain. There is support in the literature for both choices. Alvarez and his colleagues (1989) discussed "local wound pain" and show by means of a comparison table that pain is scored very low under a number of occlusive dressings. Out of a possible score of ten which would indicate a "very painful" rating, the highest recorded score is 1.97. They state that "It is probable that pain reduction is due to the insulation and protection of the sensitive nerve endings by the occlusive dressings"(p.41). The pain relief associated with the iodine based products is supported by the research of Ormiston and colleagues (1983) who, on using cadexomer iodine on twenty-seven patients with venous ulcers found that: "The reduction of pain was in some instances very striking and occurred within a few days of starting treatment"(p. 65-66) and by the work of Grennert and colleagues (1983,p.55) who found in a study of thirty four patients with chronic wounds that the sixteen using a cadexomer iodine product had more effective pain relief than those on their standard treatment. Similarly, Lindsay and colleagues (1986, p.141, 146) in reporting the findings of their study of twenty-three patients with exuding venous leg ulcers state that those treated with cadexomer iodine dressings show a statistically significant ($p<0.002$) decrease in reported pain, odour, oedema, erythema and pus when compared with the group treated with a standard non-adherent dressing and support bandaging. These wounds, although sloughy, are not described as infected. The bacteriological reports show fairly ordinary organisms such as enterobacter and staphylococcus aureus but pseudomonas and streptococci were also discovered.

“Cadexomer iodine treatment resulted in elimination or decrease of organisms in most cases, and this was associated with improvement in the ulcer” (p.146).

It may simply be that “silent infection” is recognised in an indirect way and treated by iodine based dressings. There is evidence to support this as an indirect pain relieving strategy, but in the short term it leaves some patients in severe pain. In addition, if the wound is not assessed for the presence of micro-organisms and the bacteriological load established in the wound, then iodine may not deal directly with the source of the patient’s pain and a slow reduction in organisms and pain may be the result.

c) Compression therapy

The other common approach to pain management is through the control of oedema by compression. “High pressure backflow into the skin of the lower leg is known as venous hypertension” (Cornwall, 1992, p.1). In venous hypertension “capillary pressure is increased and fluids, including plasma proteins and even red blood cells, exude into the extravascular space” (Dale, 1990,p.63). In addition, the deposition of pericapillary fibrin creates a barrier to diffusion and tissue necrosis may result (Browse and Burnand, 1982, p.243). The external support afforded by various bandages counteracts this pressure and it is the reduction in fluid pressure in the superficial tissues and the improvement of the tissue perfusion that accompanies it, that is expected to bring about pain relief. Ertl (1992, p.546) discovered that 67 percent of the patients in her study had “pain in their affected limbs” and she found a statistically significant positive correlation between oedema and pain. Compression is a logical way to tackle pain in the appropriate patients and with correct technique.

However, unless accurate assessment of vascular function precedes the application of compression, dire consequences can and indeed have resulted. Callam and his colleagues (1987c, p.1382) report that in Scotland one third of the surgeons (N=154) have seen patients in whom damage to the legs was caused by compression. The forms of compression mentioned include compression bandaging, elastic stockings and anti-embolism stockings. The

damage reported in that study ranged from ulceration to necrosis and of a total of 147 cases of injury, seven patients needed to have reconstruction of the arterial supply and in twelve patients amputation of the limb was required. In short, this form of treatment, although managed routinely in the community by nurses who are not specifically trained to administer it, can have devastating consequences.

One system of compression that has been developed in recent years and which aims to control oedema and to reverse the superficial effects of venous hypertension is the "four layer bandage". Blair and his colleagues(1988, p.1160) achieved a remarkable 74% healing rate in twelve weeks of treatment with sustained and graduated compression in a group of 126 patients (146 ulcerated legs) who had failed to realise healing in over two years of other treatments. The level of compression obtained by using four different layers give readings at the ankle in excess of 40mm. Hg. and below the knee it was approximately 17 mm Hg. It is recognised that "graduated compression" is the correct form of this treatment because the physiological levels of venous pressure are greater the farther away from the heart a tissue lies as has been previously illustrated. The successful outcomes of the initial study of the four layer bandage system have led many nurses to adopt this treatment. The nurse managed *Riverside Community Leg Ulcer Project* which resulted from the initial study, claimed:

"Patient benefits from the Riverside clinics were immediate in terms of relief of pain, improved sleep and reduction of anxiety. Some improvements in quality of life were experienced during the first 2-3 weeks..." (Bosanquet et.al., 1993, p.147).

This much publicised project was initiated to provide a consistently sound level of care to patients with leg ulcers. The four layer bandage system became their cornerstone of treatment for patients with venous ulcers but it was not used alone in all cases: suitable patients also had pinch grafts applied to their ulcer beds and in a separate article (Moffatt et al. 1992) it was stated that:

“Patients judged adequately fit for simple venous surgery (under a local anaesthetic if necessary) were assessed in the vascular laboratory at the hospital...” (p.390).

Although only five patients of ninety who had this in depth assessment went on to have surgery “to correct their underlying disease”(Ibid.), it is not known how these patients and those with pinch skin grafts were treated in the statistical summaries. Also important to the composition of the sample is the fact that of 475 patients treated, 50 were “too unfit to attend the clinic and were visited at home” (Ibid.). The exclusion of these patients from the subsequent analysis of costs and healing rates might also significantly affect the comparative cost figures which will be discussed shortly. The healing rates reported by the project (Moffatt and Oldroyd, 1994, p.494) indicate “69 per cent of venous ulcers had completely healed by 12 weeks, rising to 83 per cent at 24 weeks” which is truly impressive. In addition, the costings of the community based leg ulcer service(Bosanquet et al., 1993, 147) indicate a reduction of £500.00 per patient per year in such treatment centres compared with the hospital setting. However, these cost benefits have to be interpreted in the light of the calculations of which staff salaries are included: the community clinics have nursing salaries as the key provider costs whereas the hospital based clinic would no doubt have included consultant and registrar salaries. In short, the apparent advantages may not be as great as initially thought. In their article in the British Medical Journal, (Moffatt et al. 1992) the authors admit:

“Despite the success of this service in treating ulcerated legs it must be acknowledged that reulceration is a major problem in these patients” (p.1392).

Approximately 20% recur within six months and 33% by a year despite both ongoing compression and follow up visits from the staff of the clinic. The part of this story that is widely known by nurses is the success side and an analysis of the actual costs and healing rates with follow up statistics has not been reported widely in the nursing press. Indeed, the presentation of the findings is so dispersed in the literature that one needs to have four very

different literature sources to obtain anything approaching a complete picture of the therapy. It has become very much the treatment nurses aim to provide despite the fact that the four layer bandaging system is not available on prescription in the community.

After an initial presentation of findings as long ago as 1988, this situation is surprising and perhaps confirms this writer's view that the results are not at all as clear as the nurses were initially led to believe. During the course of this study a community clinic was opened in a nearby health authority to evaluate the "four layer bandage system" and more recently, the drug company that manufactures the products has offered supplies free of charge to a group of community nurses in another health authority who wish to set up a leg ulcer clinic and conduct a clinical trial. The limitations of the Riverside Project are not generally known amongst nurses and the researcher could find no District or Practice Nurse who had any doubts as to the efficacy of the bandaging system.

The nurses are indeed keen to use this system when they are able to obtain supplies. One way that this is achieved in the absence of a clinical trial is for the nurse to have the patient referred to the consultant clinic with the request that the patient be assessed for suitability for treatment with the four layer bandaging system. If the consultant approves, the prescription is obtained by the patient from the hospital pharmacy.

The researcher has seen patients assessed in consultant clinics for their suitability for treatment with this high compression system. A mistake in diagnosis of ulcer type, as noted, could have devastating consequences for the patients but even in these circumstances it is not common practice to obtain even a simple ankle/brachial index reading to rule out arterial compromise before initiating treatment. In the end, the community nurse obtains the treatment she wants and thinks to be beneficial but the patient is put in grave danger because of the inadequacy of medical diagnosis. The nurse reasonably assumes that a comprehensive assessment and diagnosis has been undertaken and that she is providing safe care by employing the bandaging system.

The four layer bandage system, although popular with nurses, is not easily obtained and it is more common to see other bandages used. Most

bandages give varying levels of compression depending on the circumference of the limb, the degree of stretch (and this varies as the bandage is worn, washed and reapplied) and the technique of the nurse. It is not uncommon to find that the nurse has applied a bandage incorrectly: some are made to be overlapped but not “criss-crossed” to achieve the desired tension and if these types are applied improperly compression is either too low or considerably increased. Both errors have the potential to cause the patient harm. Another possible problem is that compression is almost always applied to oedematous limbs and uneven compression in these limbs can cause actual cutting of the skin. There are some bandages that have shapes printed on them or lines added so that the error in application can be minimised but they are not routinely used.

In conclusion, it can be said that the approach of the nurses to pain management by compression is one fraught with potential dangers and the assumption they make that when the oedema is relieved, the pain will subside is not validated in practice. In many cases their patients are in increased pain because oedematous limbs are subjected to even further pressure. One elderly lady expressed it in these words:

“Sister would say: ‘I’m afraid you’ll have to have the stronger bandage on again and I would beg her not to do that. The dressing (zinc based wound contact layer) dries stiff. I thought I would go mad with that because I didn’t know where to put my legs or anything. I had to ring through to them (the District Nurses) to tell them to come out to me sometimes.”

In summary it can be said that nurses do not expect these patients to have much pain and when they indicate that they have pain, the nurses focus on the wound and attempt to deal with the symptom via the local interventions of assessing the wound for the presence of infection and dealing with it appropriately, making dressing choices that are associated with decreased pain and through the application of compression bandages. Over time, the approaches used by the nurses might work, but in the short term the patient’s quality of life deteriorates as a direct result.

The onset of acute pain: the early phase of ulceration

The descriptions of pain provided by the patients show an interesting and hitherto unreported pattern. The pain is most problematic to the patients in the early stages of ulceration and most distressing and difficult to bear at night during this early period. By the time they consult their doctors, the patients have been caring for their wounds for weeks or months and it is their deterioration into very obvious "ulcers" and the increasing pain that leads them to seek help.

Pain in the prodromal period

Pain in the early stages of ulceration is almost universally mentioned as a serious problem by the patients. Those who have ulcers which arose spontaneously rather than from trauma describe a pattern in which the pain is worst before the disruption of the surface tissue:

"Your legs hurt more and more *until it breaks*. The skin on the outside is the last to go and, by George, you put your hand on the top of your head! The pain is terrible!"

"It doesn't begin to stab *until it gets to breaking point*."

This type of ulcer, particularly when it recurs is perhaps the most tragic because, in these cases, the pain could have served as a useful warning sign. However, this does not happen because the patients and their nurses lack the knowledge to guide them into an effective intervention strategies.

Night pain

Night time is noted almost universally by the patients in this study as a time when the pain is increased. This experience is associated with either the heat of bedclothes and/or the difficulty in finding a position for the ulcerated limb in which no pressure is exerted from the surface of the bed or the bedclothes:

" Sometimes I'd have a pillow and put my leg outside the bed because if it was cold, it seemed better. Well, even now when we go to bed, if the heating has been on, I think: 'Oh, it's warm!' And I can't bear my legs hot. I can't sit in front of the fire or anything. I can't bear heat on them. And there's me with my feet sticking out of bed and his feet are just like blocks of ice!"

"When I used to go to bed at night if you were laid like that with your heel resting on the bed it were painful. You couldn't turn it that way for the other one (ulcer on the other leg). It used to be sometimes a real painful job!"

"Oh, I couldn't sleep--I couldn't walk--You know, if I was walking you feel as if your leg is in a vice! I couldn't sleep at night. I was taking Co Codamols--you're supposed to take eight--that's the limit. Well I was taking twelve. In fact when Distalgesic was on the market for ulcers I took as many as twelve of those a night. I know I sat up in bed and cried with the pain. Before the latter part of last year I was sleeping downstairs because I couldn't lie upstairs on the bed because, you see, I have them(the ulcers) on both sides, and no matter how you lay in bed you lay on an ulcer. They are VERY, VERY painful. I didn't have a full nights sleep for ages."

This last patient highlights the importance of having knowledgeable health professionals involved with pain assessment and management. The use of Distalgesic (Co-Proxamol) is dangerous in the dosages described. It is composed of paracetamol and dextropropoxyphene. Prolonged use of paracetamol may cause liver damage and propoxyphene, having a long half life, is liable to rise to toxic levels administered in larger dosages over shorter spans of time. To be effective as an analgesic, this drug combination requires regular administration and is unsuitable for occasional use. Professionally competent nursing management, or medical prescribing might have afforded her protection from the potential dangers of overdose and provided the analgesia she required.

Another lady in describing her pain in the early days of ulceration gave a picture that indicates how the doctor approached pain management: like the nurses, he focused on the needs of the ulcer and obviously failed to appreciate the needs of the person with the ulcer. The disruption to the patient's life is all too graphic.

" When I was working at the garage they were really bad; I had the real peak then. They used to gnaw. I used to be on the settee (rather than sleeping in her bed) for six weeks at a time then because they were so painful. The doctor used to say to me 'Get as much rest as you can' but I have never, never been one to put my feet up. When I was sat down, I was sat down but never with my feet up. Oh, I used to try to put my feet up and rest my legs but I used to find as soon as I got my legs up the pain used to be more and as soon as I got into bed at night, again the pain used to be terrible, so much so that I used to get up and lie on the settee with my leg hanging down resting on the floor because I couldn't rest any other way. I know at that time I couldn't get hardly any sleep with it".

This patient may appear to be giving information indicative of an arterial ulcer but her comment about resting her leg on the floor refers to her need to position her leg so that nothing touched her ulcerated areas. This approach to relief is also seen in the quotation below:

"Well it's all right now, but when it got real deep the pain used to be bad at night ; it used to wake me up and I couldn't sleep. I used to sit on the bed and let the blood flow. That's when I was working years ago, you see, when I was standing all day—it was very bad then, the pain. But over the years there is very little pain; they don't seem to hurt much but you'd think they would because they are so big like. You think it would hurt. Well, I don't know, you probably get used to it or its just numb. Well, they don't hurt and they don't keep me awake at night now."

Descriptions of the ongoing pain

After the initial period of intense acute pain that may last for weeks or even months, the pattern of pain changes. The ulcer becomes *generally* more comfortable with feelings of heaviness and dull aching occurring after prolonged standing. By this point the patients have learned ways to minimise their pain and discomfort:

"It's a funny pain. You know it's there but it doesn't get at me. I don't know whether you can understand that. I know it's there at the present moment; it's just a bit sore. But as I say it wouldn't stop me from going out; I would still go. Just at the back of your mind you're thinking: 'Well maybe I shouldn't have done this; maybe I should have sat down.'

"Well to start with it (the pain) gradually got worse and was sorer and sorer. It's funny to explain it--sort of a smarting, burning pain you know, and that was always present. In fact at night when I got into bed I had a job to get to sleep at all with it. That was for probably three or four months it was like that. Then, gradually it--the pain has gradually gone you know. But it is still not healed up yet. If it aches in the evening I usually get my leg up on a chair and that seems to ease it. I've noticed exercise seems to do it good too"

"At first because it was so bad, I never slept hardly at all but now I take two of my tablets before I get into bed and I sleep the night"

Question: "Do they hurt now?"

Answer: "Occasionally, but nothing like--I don't know how to explain it--when I get out of bed in the morning and put my foot to the ground, then I get it, which makes me think it is the veins hurting. But it is not a throbbing pain; it is just an uneasy pain. I don't know how to explain but it's certainly not that gnawing pain I had before"

"It has good days and bad days now--nothing like when it first started."

The initial acute phase gives way to an ongoing experience of discomfort and aching; the worst period seems to be over. The onset of this period of lesser pain is not necessarily associated with wound healing and in fact the overall condition of the ulcers might appear to be far worse to the patient. During this period it is very easy for the nurse to overlook the discomfort and pain the patients experience. However, the patients have recurrences of acute pain throughout this period and it is sporadic and apparently unpredictable. This problem is by no means minor but it is routinely missed by nurses.

Intermittent acute pain

Although the general experience of pain lessens over time, it returns in an acute and intermittent form that is extremely painful for the patients. The descriptions are vivid and although these attacks are of short duration, lasting from seconds to a few hours, they are obviously intense.

"By gum! Well this one hurts terrible sometimes! It's like a throbbing--all the time: grip, grip, grip! Then you drop off to sleep, then all of a sudden its right at the top of the leg to the bottom, and right down there and at the back--it's that sore! It's the full leg; it affects it all."

"I can't really describe it. You just get this sharp pain and it makes you put your hand on top of your head! It's right in the middle of the ulcer. I used to pick up my leg quick and my husband used to say 'Now what's the matter?' And I would say: 'It's that damned ulcer' Oh I shouldn't swear, should I? But you know, it takes a lot of describing but they are painful they are"

"It's like somebody sticking a knife into you. It's right up the leg--jab, jab, jab!"

" Sometimes it were painful and sometimes it wasn't so bad. You know, you could be sat doing nothing or outside and all of a sudden it used to strike. It always reminded me of someone trying to stick needles in you and such--just a real digging sensation and then, you know, it might last several minutes and then gradually fade away so it were not so bad."

"It was like someone sticking needles in the whole day--pinching! The only time the ulcer gets to me really is on the days it gets *very painful*. Doesn't seem to have any pattern or reason. I mean one day I can do my shopping, wash, do my garden and it doesn't bother me a bit and then one day when I rest it, it hurts. I don't know, I just don't know what the answer is."

"Well sometimes, some days it feels a lot better. It feels normal-as good as the other leg. Then it may start and smart a bit --maybe for an hour or so and then it goes off again."

This particular type of pain would be virtually impossible to treat with analgesics; its unpredictable occurrence and duration would make pharmacological interventions difficult. However, it might be successfully managed with transcutaneous nerve stimulation(TENS) which is a safe, relatively inexpensive and widely available approach to pain. No one has yet researched its use in this patient group but it would seem to be a useful intervention to consider.

Professional deafness

Despite the willingness of the patients to share their experiences freely with the researcher, few continued to discuss pain as an ongoing problem with their doctors or nurses. In fact, they learned quite quickly that such discussion was not effective because the nurses simply did not hear what they were

expressing about their lives and their reactions to their condition and their doctors prescribed analgesics for general safety instead of for their specific needs. This "professional deafness", as I have termed the phenomenon, arises in situations where the professional focuses on a sign or symptom or a general characteristic of the patient, such as age, and fails to hear or appreciate the experience of the patient. In the case of the nurses in the study, it arises when the doctor refers patients to them with the *sign and symptom specific diagnosis* of "leg ulcer". The level of medical diagnosis that the nurses need is a *condition specific* one of "venous ulcer" or "arterial ulcer" for example. If they were to receive a *condition specific medical diagnosis*, then that information would have been a key component in their nursing assessment of their patients. Without that essential component, however, they become selectively attentive; they do not hear the patient because their attention is focused upon the wound. That missing medical diagnosis has to be made, however inappropriately by the nurses, because, without it, they have no sound basis to guide their ongoing treatment.

Initially a number of patients mentioned their pain to the doctor and most of these people were prescribed Co-codamol which was generally ineffective: "Well, it eases them a bit" was the usual reply. Having asked the doctor once for help with the pain the majority of the patients perhaps assumed that if the first prescription was not helpful, then there was not much point in returning for another prescription. In addition, after the initial consultation most patients had been referred to the nurse and therefore they did not have routine access to the doctor. The exceptional few patients who persist in discussing their pain do not usually fare any better than those who abandoned this approach earlier on. The patient quoted below was given "something for pain" but she indicates clearly that Paracetamols were her mainstay:

"Dr. X said she could give me something for pain but I can't remember what that was—just on that stage that was. When they got so bad where I couldn't really stand it I would take Paracetamols"

Question: "Were they adequate for you?"

Answer: "No, not really. I don't know if you have spoken to anyone else with ulcers but anyone would tell you that it is a horrible pain—it gnaws at you all the time. It eases from time to time but...."

Another patient who was persistent indicated just how deaf to her words the nurses were:

"She said: 'It's come up to the top now, it's looking well now' but I'd said the soreness is there, it's terrible sore, yes its sore up there and around the back of the leg—I keep asking them if there are anymore around the back of my leg and they say no. They have examined it well but they say no"

Most of the patients feel they need analgesia but most purchase over the counter drugs for this purpose. The most common drug choices are Paracetamol and Aspirin but the required analgesia is not obtained:

Question: "Did the Paracetamol take the pain away?"

Answer: "No, not really"

"Well, I take occasional paracetamol for my ulcer."

Question: "Do you find them strong enough to eliminate your pain?"

Answer: "Not really"

One patient took a more novel approach to his pain:

"I've gone out with it aching like anything, but after three or four pints of beer—it's like a drug, isn't it—it takes the pain away. I also take Panadols"

Other patients manage by using analgesics prescribed for their other medical conditions: "Distalgesics—I got those for my arthritis—it helps, but you're never pain free."

The reluctance to see the doctor for a prescription for analgesia is explained by one patient was follows:

Question: "Did you mention your pain to the nurse or to the doctor?"

Answer: "I did to the nurse and she said: 'Well you could get some pain killers, you know' but I didn't bother because I think you're better without drugs if you can manage at all. Plus, the doctors are always busy; you don't like taking their time up, do you? I tend to think they'll think you're wasting their time."

Managing the pain: expected solutions

The first stage of effective pain management is a belief that pain is what the patient says it is and exists when the patient says it does.(McCaffery,1968, 95). The pain that patients with venous ulcers experience is less than routinely assessed. Roe and her colleagues (1993, p.304) in a study of 146 community nurses caring for patients with chronic leg ulcers found that as many as 55% do not assess pain in their patients. Similarly, in this study, pain is not routinely mentioned as being an important assessment factor by the community nurses interviewed. There is a number of possible explanations for this but the nurses themselves indicate an almost unquestioning acceptance of the less recent medical and nursing literature which has informed them that pain is simply not a problem in these patients. When pain is noted it is viewed as a diagnostic factor that helps to differentiate between ulcer types; it is rarely seen as a biographical issue. What the nurses see very clearly before them is a problematic wound and all attention can easily be focused upon this most obvious sign of pathology; pain if noted can be attributed to local factors and treatments can be presented in such a way as to make them appear as interventions to combat it. A worrying finding in a recent study by Brunier and her colleagues (1995, p.442) is that 44% of their sample of 514 nurses agreed with the statement that "the estimation of pain by a physician or a nurse is more valid than the patient's self-report". In short, a considerable number of patients can expect to receive the attention to pain that their health care professionals deem appropriate. Walker and her colleagues (1990, p.1158) found that nurses tend to "overestimate the level of least pain and to underestimate the level of worst pain" and few used formal pain assessment tools. If the nurse's view is the one that dictates the treatment offered, then only by gaining a true understanding of the patient's experience will the patient receive the care he requires and deserves. In addition, nurses may need further education to appreciate the differences between chronic and acute pain behaviour and to become more aware of the fact that physiological and behavioural adaptation occur very early in the experience of pain but that "the patient may continue to hurt just as badly" (McCaffery and Beebe, 1994,p.21-22). Unless pain is routinely and professionally assessed and the patient's statements believed as

a true representation of their reality, the experience of these patients all too quickly disappears from the professional's view and patients are left to suffer as a result.

A District Nurse who was very interested in wound care and the management of chronic wounds in particular said:

"Well, you have to try to identify what is causing the pain. And it's very simple to say: 'Oh, that's infected, that is painful' but it isn't necessarily the case. Often you've got localised inflammation and often the dressing itself has been causing the pain. It's only doing a total patient assessment that you can try to work out what the problem is."

A change in nurses' beliefs and attitudes is the essential first step. Comprehensive assessment of the pain should follow with particular examination of disruption to the patient's quality of life. As Sofaer(1992, p.50) states "Pain is assessed *with* the patient and not *on* the patient." Planning effective interventions with the patient should follow and a plan formulated to ensure regular ongoing evaluation of the results of the interventions.

It is the discrepancy in focus from the outset of the relationship between nurse and patient that leads to a number of ongoing problems for both parties. As the nurse only infrequently comes to know her patient as a person in biographical context she works with vague and unfounded generalisations never quite meeting the needs of the patient. The lack of personal rapport and indeed the lack of professional handling of this situation on the part of the nurse causes the patient to make assumptions and to draw conclusions based upon his own very limited knowledge and it impedes his process of normalising. The ongoing disruption caused by the inadequate trajectory management will be discussed in the following section.

Part b) Hidden anxieties and disordered lives

The reciprocal impact of the illness and its management cause considerable suffering and disruption to the lives of the members of this patient group. Their comments discussed in the previous section indicate that their unheard descriptions of pain lead to prolonged periods of distress. In particular their physical pain is seen to disrupt sleep and cause them to alter the pattern of their days to accommodate the need to rest or to elevate their legs from time to time. Although the management of the pain trajectories is the main way in which the reciprocal impact manifested, there are a number of other ways in which significant biographical disruption occurs. Problems with the presentation of self become quite pronounced and these are directly linked with trajectory management and in particular, with the assumption of the navigating role by the nurses. When a nursing response that more closely resembles piloting and supportive assistance is seen, the distortions to daily life are lessened. However, all the patients have considerable work to do because of the way in which their care is managed by their nurses. In particular they have information and normalising work to do.

Information work

The patients included in this study did not know the physiological cause of their ulcers because the doctors had not defined it and the nurses were technically unable to do so. They may have been given the diagnosis of “venous ulcer” as a convenient label but it was not used as a focus for patient education. It could perhaps be compared with the medical use of the term “viral infection” which although it has meaning would not guide specific nursing interventions in terms of health education. The label of “venous ulceration” is used then, by default whenever more obvious choices are not indicated. In this unusual situation the patients are given what might be called treatment related, or lifestyle instruction rather than health education. They are instructed in a series of do’s and don’ts that include: leg elevation, compliance with compression, leg exercises, protection of the skin of the lower leg from chaffing and injury, and keeping the bandaging dry. In this limited way they are able to

cooperate with their treatment that had been determined largely by their nurses.

The nurses, without exception, make the assumption that the patients do not really want to know about their condition. They insist that, whereas they are willing to teach them, most patients simply want them to heal their wounds. This notion is quite unfounded. As will be seen from the patients' statements, questions and activities, they go to considerable lengths to gain knowledge. The lack of awareness on the part of the nurses of these needs raises important professional issues because it is through the process of health education that nurses can maximise the health potential of patients. Redman (1993) states that health professionals should regard:

“all interaction with patients as contributing to the broad process and objectives of teaching and learning. Each time providers are with the patients, they are assessing patient needs. Often these needs can be met by providing patients with information, clarifying their thinking, reflecting their feelings, or teaching them a skill”(p.8).

She, like Henderson (1966), and Corbin and Strauss(1992) believes what has been undisputed for most of this century: that imparting knowledge relating to health is a nursing function. The purpose of patient education is to alleviate anxiety, give a sense of control and allow “ involvement in decision making and awareness of the alternatives *and the anticipated consequences* of each alternative course of action” (Miller, 1992, p.12). Chasse (1991,p.120-121) makes the important distinction between patients being given information and having mastery of it. It is clear that to manage one's own biography effectively, especially in chronic illness, one requires a sound knowledge of the trajectory.

Information is not deliberately withheld but it is used in a problem solving way by the nurse. Her focus is twofold: it might help the patient and it also gives her valued information about the nature of his pathology. For example, if she instructs her patient to rest with his legs up above hip level and he reports that this causes increased pain, then, this fact is indicative of arterial involvement. If he reports to the contrary that such action eases his pain, then her view of his ulcer as caused primarily by venous problems is supported.

The patients know well what actions they should take but they are not content with the limited information given to them and they go to considerable

lengths to gain the knowledge they require in order to place their unusual experiences within a framework they can understand. Nothing prior to the development of the first ulcer has prepared them for the situation in which they now find themselves. Although venous hypertension might have been present perhaps for years before the ulcer formed, they did not recognise any of the insidiously occurring changes as part of a chronic illness trajectory. When their wounds do not heal, they seek explanations and the conclusions they reach are often unnecessarily anxiety provoking and socially isolating.

Not one patient interviewed for this study indicated a more sophisticated knowledge of venous ulceration than: "It's something to do with the veins" or "I know it is bad circulation. I don't really know an awful lot more." Yet, they want to know and when the information is not forthcoming from the nurses they begin to seek more widely and in some cases to fear the worst. Like the terminally ill patients studied by Glaser and Strauss (1965, p.55) who became suspicious, but who lacked the medical knowledge to interpret their signs and symptoms, each patient with a venous ulcer has to build the cues into a meaningful pattern, placing a variety of indicators together to form "an accurate and complete answer." However, because these patients lack the definitive diagnosis and because no one else they could consult holds this answer with confidence, they never reach their goal.

Their search for meaning however is extensive and outlined below are examples of their strategies. Some asked the interviewer questions and in contrast with the commonly held views of the nurses, the questions could be quite specific:

"Can I just ask you something? If this Sorbsan (a type of dressing) had worked and the ulcer had healed with it, what sort of percentage success rate do you think....I mean, do they always break out again?"

It is important to note here that the patient is not certain or convinced of the chronic nature of her situation or the future implications of her condition and therefore she is seeking confirmation of a professionally held trajectory projection.

Others state that they have read articles and tried to learn more from books: "I sent away for a pamphlet on ulcers—there wasn't an awful lot in the pamphlet that I didn't know but diet was mentioned." Some indicate that they have discussed their condition with their doctor in an effort to elicit information: "The doctor said: 'No it's nothing to do with your heart; it's just bad circulation.'" However, sometimes this approach causes more anxiety as is illustrated in the following lady's statement. She had hoped for reassurance from her doctor and instead, had her worst hidden fears confirmed:

"For a long time you think it's not going to get better at all, even so far as the doctor to come in—because he looks at it every now and again when he is around. And he says "I don't think we're going to have to take your foot off after all"—which sounds funny but all sorts of things go through your mind, when you think to yourself. I think probably you know too much about ourselves these days and you worry about things unnecessarily. You wonder if it could be affecting the bone, or whether how deep its going inside. So I think it's important to be reassured."

The lack of sensitivity on the part of the medical and nursing staff is sometimes marked. The incorrect assumption that the patient knows the remarks are made in a light hearted fashion and are not to be taken seriously leaves the patient more distressed because of an encounter with health professionals.

Reflection also plays a large part in the patients' search for answers and meaning and nearly all state that they reviewed what they have done to cause a prolongation of their wounds or an exacerbation of their symptoms. If they can find a reason in their actions, then perhaps they can alter the experience and reach the dreamed for goal of wound healing:

"I couldn't think of anything that I'd done differently that day before I decided to have a rest day and I have rested with my leg up quite a lot(because of pain) and by evening, well, I don't know, it doesn't seem to like resting. It's strange, but I find ulcers are more painful in the evening—I suppose that's because you have been on your legs and the circulation gradually not going where it should do at the end of the day and of course your feet tend to swell up a bit in the evenings—well, mine do anyway."

"It wouldn't stop me from going out—I would still go. Just at the back of your mind you're thinking: 'Well maybe, I shouldn't have done this; maybe I should have sat down.'"

By attributing the prolongation of the ulcer or symptoms to personal action, the person is able to relax somewhat believing that, had he or she complied more closely with the instructions from the nurse, then, their ulcers would have healed or the symptoms been resolved. In fact, many of the patients express a feeling that they have not complied as well as they have been asked and they feel guilty about this fact. Many appear to blame themselves for the failure of their wounds to heal which again, reinforces the assertion that these patients have not been given any health education of significance. The following quotation is typical of this self blaming attitude:

"I think it's my own fault because I didn't take enough notice of them(the nurses) when they first started. I mean I was supposed to rest and I didn't—and I don't. Well, I don't rest as much as I should. You're supposed to rest with your legs up. Well, most people find themselves thinking: Oh I can't be bothered. So I think had I been wise then as I am now, I wouldn't have been in this position. And also I worked at the post office then. Before then I was working early mornings and you don't take your bandage with you and the thing was then not to let it inconvenience your way of life—your work and that—you sort of put a bandage on and hoped for the best. But I blame myself as much as anything."

Many patients seek information in comparisons and consider how they are faring compared to others whom they know have ulcers. Those who are friends discuss how each is faring under the current treatments and when similar rates of healing or similar experiences are recounted, each takes heart that she is not unusual. For those who attend "leg ulcer clinics" there is a good opportunity to discuss ulcers and often to see other people's ulcers. As one lady said, she saw many over her time of treatment at a local hospital: "They used to undo them and I used to think: 'that's worse than mine.'"

The use of a comparison group allows the relative normality of the individual experience to be evaluated and even when the ulcer is deteriorating or causing pain, comfort may be taken that the personal situation is not "as bad" as many. However, through comparison, others who are worse off are

demonstrating clearly the range of signs and symptoms along the same trajectory and this in itself is a source of worry. For those who lack personal knowledge of another sufferer or who do not attend the dermatology clinic for ulcer care, the use of the nurse provides a link and information:

“This lady in our village, hers is as big as the palm of your hand. I haven’t seen it, like, but I asked Sister J: ‘How’s Mrs. T’s ulcer now, because I haven’t seen her for a week or two?’ She said: ‘I’m afraid it’s not very good—it’s a really nasty one she’s got’ So I thought to myself, I thought, well I hope mine doesn’t get so big, you know. You’re just bound to get these worries aren’t you?”

As can be readily seen, these patients are not disinterested in learning about their condition; they are actively searching for meaning. Like their nurses who are unsure of their accurate medical diagnosis, the patients focus on the obvious: the ulcer, and they look for a diagnosis that will make sense to them of their non healing wounds and their pain. However, unlike their nurses who are, for the most part, quite unaware of the impact of the illness upon them, they have a complete knowledge of the disruption being caused to their individual biographies and this adds to their anxieties becoming part of the evidence they weigh in searching for explanations. Their worst fears are of gangrene, deterioration and of amputation and they are largely hidden fears. They do not want their nurses to think them “silly” and so they do not ask directly for information but continue to search indirectly for answers. Their worries are quite real and sometimes veiled beneath humour or attempts at bravado:

“I try to keep my life as normal as I can.....I will do my work as long as I can...I may get into a position where it will get really bad but I will think about that when it comes—not now. You can’t think about that, can you? You can’t think about what may come. I don’t want to know. If I had a chance I wouldn’t want to know –if somebody said ‘You have a year to live’—like saying you were going to get a cancer and you’ve got to do this and you can’t do that and you may live eighteen months. I would say, ‘Well (laughing),I will live for a year and just enjoy myself”

These words come from a 42 year old man who has been appalled by the ulcers he has seen at the clinic. He confided that if his leg deteriorates to the point of some that he has seen, then he intends to commit suicide. Interestingly, this patient is a man who is seen by his nurses as “cheeky” and a “bit of a lad, really” and when I was going to interview him I was advised that I would be all right as long as I followed the advice to :“give as good as you get”. His deeper pain and fears are well hidden and even a prolonged association with him has not allowed these to be glimpsed.

There are others who seem less worried about expressing their anxieties although they are often cloaked in phrases that allow the listener to dismiss the worries with the patient uttering them as “silly” or “dumb”. In the following example, the patient protected himself from possible ridicule by prefacing his statement with “I worry about stupid things...” By labelling a real fear in this fashion, it becomes safer to talk about and easier to expose.

“I worry about stupid things, like what it is doing to your leg, what's underneath the ulcer—if you could lose your leg because of it—you know.”

Others have less difficulty in bringing worries to the surface as legitimate concerns:

“I worry about how far it is going inside my leg, is there any danger of gangrene or deterioration—them sort of things worry me anyway.”

“Well, I worry that it would get larger, start to grow bigger and start to eat down into my leg more.”

“I asked Doctor when he came to see us if it was gangrene or a cancer. The way it was spreading I was worried.”

The fears are widespread and very real. Perhaps because their experience to date has been of “professional deafness” to their pain and worries and because they lack health education to place their condition within a known framework, these patients become fearful of recurrence, deterioration, and they come to fear being near anything and anyone who might damage their legs. One lady summed up the ongoing and pervasive nature of her concerns:

"Well, I suppose to me it's an open wound and I'm always very frightened of getting infection in it, and worrying if you knock it, for example, particularly in bed at night –I toss and turn a lot and at night, although I take the big bandage off, I always do have the ankle bandage to protect it in bed and probably always will from now on. I think I'll be nervous of it forever even if it does heal. I say "even" because at the moment you can never see what it is going to do . It's really frightening to have this. Although I've had a lot of pain before it has always been where nobody could see it—arthritis—and nobody knows but you just how bad it is, but when you've got something you can actually see and other people can see, you need a lot of reassurance really."

It is noteworthy that the visibility of the condition makes it worse for many patients. That leg ulceration is a stigmatizing condition is completely absent in the literature. It can easily be linked with that other discrediting attribute of being "old" and the not unfounded fear is that those who come into contact with the individual will, on the basis of the general information obvious to them, "apply untested stereotypes" (Goffman 1959, p.13). This situation focuses attention on the normalising work of the patients and this will next be discussed. However, before turning to that issue the question remains: why are the nurses so unhelpful in terms of information needs for these patients?

The lack of teaching: a question of focus and competence

As has been stated, until recently, no one has questioned the assumption that teaching is an integral part of the nurse's role. It is therefore surprising to find that the patients in this study have such striking information needs despite regular contact with their nurses. A number of explanations are available. Two reasons for this have already been discussed: the nurses' general lack of knowledge related to the condition and the significant bias amongst the nurses against older people with this condition. During the course of data collection I was amazed at how little the patients knew of their condition and reflected on how this could happen. One explanation I considered early on was that perhaps the nurse caring for the patient in the present works on the assumption that the previous nurses who dealt with the patient earlier in his patient career had explained the situation fully to him. The work of Kruger(1991) lent some support for this idea as she found that nurses are very poor at recording and

assessing their health education work. However, subsequent interviews with the nurses did not confirm this.

One wonders how widespread this lack of knowledge might be in patients with chronic illness in general. In a study of patients diagnosed as having diabetes for an average of 6.3 years, Thomson et al.(1991) found that there was no significant difference in the knowledge of the symptoms of hypoglycaemia between them and the non diabetic controls. Over half attended a specialist diabetic clinic and the rest were cared for by general practitioners. One might have assumed that all patients with diabetes would have received an effective educational package to assist them in self-care: this is obviously as ill founded as the assumption that patients with leg ulcers will know the nature of their condition or the rationale for treatment. The researchers conclude that there is a need to look at the education of the older age groups in particular but it may well be that these findings could be repeated with any age group.

Surprisingly there is only one small study that explored the use of patient education in the healing of venous ulcers. *Although it took a very normative approach to what needed to be learned, it is of interest because it showed positive patient outcomes.* Nudds (1987) stated that her study was based upon the assumption that "Patients need knowledge of their condition before they can understand their treatment and co-operate with the doctor and nurse. They must be able to accept their leg ulcer and recognise their role in promoting healing" (p. 12). She used a convenience sample of 9 patients, six of whom were placed in the intervention group and three were used as controls. Having measured their ulcers at monthly intervals for the three month period prior to the education program, she had baseline information on their ulcers. She also measured the patient's knowledge before and after her intervention; in general the level of knowledge of their condition was very poor (3.5% on average, with a range from 3.5-84%) She taught the intervention group about their wounds, the underlying pathophysiology and explained the action of ankle movements in pumping blood out of the lower limb, and the action of compression. Her average knowledge gain after the intervention was 9.5% which sounds quite small but the improvements in terms of their ulcer size were significant at the

99.5% level of confidence. This small study seems to have been unaccountably overlooked by the nurses involved in the care of these patients but it would appear to be worthy of a larger scale follow up.

In the light of what has been discussed it is probably not surprising to find that the role of the nurse at the centre of patient education has been challenged. Luker and Caress (1989) think that it is both unrealistic and undesirable to involve trained and student nurses in the process of patient education. Their rationale for this stance includes: the complexity of adult learning, the lack of specialist preparation of the nurses in Britain for this role, the potential for patients, by virtue of their illnesses, to have special learning needs, and the lack of skill of nurses in assessing such factors as literacy and motivation. They conclude that it should be considered "impractical" to expect nurses to assess patients' learning needs on a regular basis. Although much of their argument may be valid, the influence, if any, of the stated elements on patient learning outcomes is unknown and surely this must be the key factor of interest in this matter.

Interestingly, their proposed solutions, that formal patient education should be a specialist function or possibly achieved through computer assisted learning approaches, fails to appreciate some of the other findings from the study by Tilley et al.(1987):a) that the patients (N=38) "felt more comfortable about asking questions of nurses when in a one-to-one relationship than amongst a group of patients" (p.298), and, b) that patients considered as useful, not the more formal teaching they were given but rather the "content that explained for them what had happened and provided a prognosis of what to expect in the future"(p.299), that is, information that had meaning for them within the context of their lives.

That there are serious issues to address in patient education is readily accepted. The central issue, however, is missed by Luker and Caress: patients may need to gain information or skills in order to deal with their changing health status and rather than summarily excluding the generalist nurses from this task it would seem more reasoned to study the effects of present teaching approaches and to ask simply: "Does it work?" before recommending alterations which may or may not be appropriate and acceptable to the

patients. Assessing the information patients require and determining how they as individuals wish to attain it would seem appropriate approaches.

There is a very nurse centred orientation in many of the studies of patient teaching; the nurse is seen as the key educator and the patient is therefore seen as having a more or less dependent role upon her. This approach is not appropriate in chronic illnesses, where the complexity of the learning required extends far beyond the medical and nursing orientation into the biographical. "Effective self-management requires collaborative decisions about treatment regimens, monitoring of health status, judging the effects of regimens, and communication with the health care provider" (Bartholomew and Schwartz, 1991, p. 214). Collaboration and not professional domination of the field are clearly required in the management of chronic illness.

The patients perspective

The patients in this study try to gain information from a number of sources, many of them medical and nursing. That this approach fails to provide them with the answers they require or the support they feel they need is clear. Perhaps this situation is more widespread than competent practitioners would like to think. Patients clearly indicate from their participation in self help groups that their learning and adaptive needs are not being met by the professionals. Strauss et al. (1984) states that "Self-help groups are among the more amazing phenomena of the last two decades. They are now very numerous, many of them organised around the chronic illness concerns of their members"(p.111). Maine(1984) notes that these groups are a "hot topic" amongst health professionals not simply because of their increasing numbers but because they can be seen as "confirmation of the dehumanization of health care agencies and institutions"(p.112). He found the members in his study of diabetic self-help groups met for two reasons: education and social support. These functions are common to self-help groups. The Multiple Sclerosis Society, for example, indicates in their literature that local branches are managed to reflect the interests and concerns of their members and that they provide both social support and practical help. In addition, the educational function is highlighted by their comments concerning their national help line: "Not only those who

have MS themselves may find it helpful to talk things through or gain reassurance from accurate, honest information, but people who are close to them will have their own particular concerns and worries" (1995, p.3).

There is an obvious need for information work and the way in which the health professionals manage the care of this patient group makes it more difficult for this work to be accomplished. Whereas it would be unrealistic to expect the nurses to make personal information work unnecessary, it is surprising that they fail to provide even the essential beginning elements of information that would, at the very least, minimise anxiety for their patients.

Normalizing work

Ordinarily, information work is the bedrock of normalising work. When health teaching is provided as an integral part of individual patient care, then it can be specifically targeted to assist the patient in resuming his normal biographical activities or in minimising the impact of the illness and its management. Through the process of supportive assistance any particular problems with the body, biographical time and self would be elicited and become the focus of planning and intervention. In the case of the patient with a venous ulcer, this pattern is sometimes approached but never achieved and the patients who are never given adequate health education have to attempt to normalise their lives as best they can without the benefit of essential knowledge. In many cases, this situation leads to less than optimum adjustments being made but these patients have lives to lead and as chronically ill people they are "engaged in managing and shaping their lives in the face of physiological impairment and medical intrusion" (Strauss et al. 1985, p.193). They simply do the best they can.

The escalation in symptoms that leads to medical consultation brings with it a period of social disruption for all and social isolation for some. In the early days of professional navigation most feel that they are acutely ill and do not attempt to restore normality because they assume it will follow automatically once their wounds have healed. However, as the long term nature of the condition becomes apparent, the patients have to develop their own strategies to deal with the assaults to their normal lives. The nurses involved with their

care usually have no appreciation of the extent of their biographical disruption and the problems with the presentation of self they are experiencing. It is the unusual nurse who is able to be consulted with ease and enlisted as an ally in this regard.

The need to normalise arises from a number of threats to normality inherent in the condition or its trajectory scheme: pain, odour, discomfort, unusual apparel, limited mobility, oedema and problems with hygiene, to name the most significant sources. The major challenge comes from the pain, which, as has been discussed, leads to periods when simply bearing the experience might be the dominant strategy. However, with little or no help from the health professionals concerned, this type of distress, mercifully, recedes over time. The reciprocal impact of the condition and the way in which the nurses choose to manage it however, causes considerable ongoing distress and disruption. Two particular aspects of the treatment account for the majority of the patients' problems: the bandaging used and the treatment schedule. These two features of nurse navigation interfere with the of presentation of self, comfort, safety and the resumption of a normal life style. A minority of nurses select an easy to apply and thin bandage that the patients might use and as these patients are therefore in control of their bandaging and the schedule of care, the disruptions to their biographies are minimised. However, because a simple bandaging system is not used by the majority of nurses and is not the prescribed treatment of the consultant clinic, the majority of patients become dependent upon their nurses for wound care. Similarly, because the nurses and not the patients have control of the dressings and treatment regimen, their work loads and not the patients' needs determine the frequency of dressing changes and the potential for disruption is thereby increased.

The patients adjust in a variety of ways: by *adapting and enduring* by *emphasising the positive* and by *negotiating for comfort*. Most of the patients use the strategy of *adapting and enduring*. This approach is associated with dependency on the nurse or clinic for ongoing treatment, a compliant attitude and very limited knowledge of the condition and options. This position according to Barofsky (1978) is a response to coercion. He views the continuum of patient activity in decision making as consisting of coercion,

conformity and negotiation. In situations where there is inequality due to knowledge differences, or health states, the balance of power is such that one person is "more in control of the situation than the other" (p.369) and as the weaker is "obligated to behave in a manner that he has had minimal input into determining" he is coerced (Ibid.). To accommodate the treatment, the individual denies his individuality and adjusts his lifestyle. In many ways this socialised response resembles the sick role behaviours expected of patients with acute health problems who, having sought competent help are then expected to cooperate with the experts by complying with treatment. The situation will have appeared to the patient in the early stages of treatment to be just that: an acute problem and not having been informed that the ulcer is a manifestation of a chronic problem, he will reasonably assume that compliance will bring about healing. This type of response is also seen in McWilliam et. al's (1996) study of the meaning of health and the process of health promotion. In exploring the thoughts of a sample of thirteen elderly people with chronic illnesses she found that "fighting and struggling" is the first of four phases. (The other components are resigning oneself, creatively balancing resources and accepting.) It is triggered by the reciprocal impact of the illness and its management:

"The impositions of both the chronic condition and the health care system engaged in the management of that chronic condition triggered the need to do battle to achieve aspirations, satisfy needs, and respond positively to the challenges of the environments" (p.5).

In the acute phase for the patients with venous ulcers it is a struggle to keep up the normality of everyday life, of ironing and washing, of cooking and cleaning: it is a turbulent period, calling for adapting, sometimes by eliciting help from family and neighbours, or by enduring. The treatments chosen produce a major obstacle to normality: presenting themselves as normal people within their usual social settings is impossible. Problems arise because of: the conspicuous nature of dressings, embarrassment over inappropriate footwear, the side effects of drug treatments, the inability to conceal bodily fluids and from social isolation.

The threat to the self concept from the altered appearance is readily apparent and mentioned by most as a cause of social disruption. This is true more for the women than for the men who conceal more easily the bulky

dressings and knee length compression bandages beneath their trousers. However, the problems with footwear are common to both men and women and no one escapes the need to choose between buying two pairs of shoes of the same style but different sizes to accommodate the bandaging, or facing the embarrassment of being seen in public with a shoe on one foot and a slipper on the other or remaining housebound until sufficient healing occurs and less obtrusive bandages are selected:

"I don't do a lot of walking because I can't. You can't get the shoes, you know. Look at that packing what is around your legs. If you were to put that in shoes, you would never get any that would be comfortable with them and they put them gamgee packs on! You feel that leg—feel the lump of packing at that side!"

The women in particular mention the unaesthetic nature of the bandages and the younger women indicate that they choose to wear slacks when possible. The older women, perhaps less used to slacks, choose other approaches when they wish to be out in public: "We've put tubigrip on top of that just to make it look better—vanity!" one said, indicating that she chose to cover the bandages with a somewhat less obvious outer wrapping in an attempt to conceal her problem. Another lady described how she put on nylons over her dressings so as to look "more seemly". It is the nature of the condition that it is the rare patient who can decide not to wear a dressing at all because these wounds tend to produce a discharge which is at best, visually noticeable and at worst copious and offensive in odour.

The mere presence of the bulky bandaging causes patients discomfort but so too does the way they are applied and the frequency with which they are changed. For example, a dressing left on too long would allow leakage to appear through the outer wrappings, or the drainage might run into a slipper or onto clothing or a shoe causing staining and sometimes leaving a lingering odour. Similarly wound exudate even from a non infected wound has a distinctive odour and this could cause serious embarrassment.

"During the first few weeks in particular it was particularly unpleasant. I was very conscious of it. I was very embarrassed really because after three to four days you could definitely smell it, particularly in bed at night. AND when you got out of bed in the morning, you felt

like you wanted to strip the bed sort of thing: it was a very unpleasant smell."

Many indicate that the bandaging affected their social lives because of its appearance and because of the drainage which again indicates that the dressings chosen are either not appropriate to the wound or that the frequency of nursing visits is insufficient for the patients' needs:

"Well, your social life, very much. I mean especially me, you see, I can't walk about with my heart problem and I'm in a wheelchair, you see. So when I go anywhere I go in a wheelchair. But it does disrupt your social life—I mean, I used to swim a lot and I can't now. It's impossible now and I did have a decent social life. Apart from the fact the bandages look—well, maybe I'm a bit vain—but your bandages look—you're always conscious of them and you're always having a look to see—like now—if they are leaking. Things like that."

The approach taken by many of the nurses or specialist clinic staff can be seen as a technique to counter defaulting with difficult and uncomfortable treatment; by maintaining control of the treatment in terms of bandages used and times of treatments, the nurses "do not involve the patient as a responsible person" (Stimson 1974, p.100). Sometimes this is described as a very rational decision:

Our policy is to do all the dressings. Most of them are ambulant so they can come in for them. We've seen too many—we've tried letting them dress them at home—but we've seen good healthy tissue getting infected again so in general we like to do it ourselves."

One can see how this extension of traditional medical authority is devolved to the nurses in these situations: the doctor has in effect prescribed the nurse who now controls the patient's care in his name.

One of the treatments for venous hypertension that is occasionally used is Stromba, an anabolic steroid with fibrinolytic properties. In the following quotation the physician and patient roles as practised will be clearly seen as will the patient's compliance over an extended period despite difficult side effects. The patient's lack of initial knowledge about her treatment confirms much of what has previously been said about the medical shaping of this condition:

I was putting on a lot of weight, a terrific lot of weight and my husband used to say to me "Don't keep on those tablets; try to get off them if you can". I asked the doctor one day if I could come off them and she said : 'Look, the manufacturers say that if you keep on those for twelve months, they guarantee you won't get any more for five years'. So I stuck those for a year and at first we thought they were doing my leg good. In the ulcer you could see new layers of skin forming, but I still was putting a terrific amount of weight on and the doctor said: 'Do your best to keep on them because your weight you can always get off at some time' which I did and it was right what she said: I didn't have any more ulcers for nearly five years. Whether I'm right, I don't know, but it seems to me I had a lot of side effects: I had facial hair—as you can still see, and putting on weight."

This patient had not been given options during her initial or subsequent consultations. She had no prior knowledge of the side effects that were predictable and of significant duration: the facial hair was present years after the drug treatment had ceased, the ulcers had recurred and more conservative treatment had been initiated. However, like all the other patients, compliance and adapting and enduring seemed rational decisions because, particularly in the early months, they believed that they are receiving active treatment for an acute problem.

Because of this strategy of *adapting and enduring* life becomes very limited. Patients recount how they loved to drive but now could not because the bandaging made the necessary ankle movements for clutch and brake control either impossible or painful. They therefore simply stopped driving. Many mention the problems they have with walking that are directly related to the bandaging and the associated need to alter their usual footwear: "I think you learn to walk in a different way perhaps. I think you're very conscious—you don't want to disturb it, do you?" Indeed, many feel they walk differently because of their treatment and some have incurred falls which they attribute directly to their changed gait or clumsiness because of the bandages. The stiffness of the ankle joints that results from compression, the feeling that ones legs are like "lumps of wood" in the bandages, the change from walking to shuffling are all mentioned.

Patients who were physically active before the ulcer occurred adapted by giving up pleasurable pursuits: "We used to go rambling a lot all over the place but uneven ground is not ideal so we don't go anymore." Some express the

desire to travel to visit with friends but decide that they could not tolerate longer journeys by train or bus when their legs would be in a dependent position for extended periods of time: "I can't go and visit my friend in Wales because I would have to sit in a train and I might not be able to put my foot up and its a long way and I think that would do more harm than good." Active people with links in the community find they can no longer volunteer to help at social or church functions because of the unpredictable nature of their ulcers:

"I do a lot of voluntary things and now I am finding I can't say "Well yes, you can rely on me to do the cake stall, or to run old people here, there and everywhere because I've got to think about this and try to get it better."

Over time the patients grow aware of the chronic nature of their treatment and some attempt to transcend the experience by *emphasising the positive*. Months or years of ulcer care have led them to become philosophical and to develop particular coping strategies. They routinely say : "Well, you can't let it get you down can you?" and "You just have to get on with your life, don't you?" "Lots of people are worse off than me." They have learned not to let the ulcer become the ongoing focus of their lives despite its often sustained presence. There are still times of endurance and adapting as before but now some have added a particular psychological strategy to help them gain a perspective and to force the chronic illness into the background as much as possible.

For the most part they feel that their nurses and doctors have "done the best they could" and "had tried everything". With time, the pain tends to decrease and this improvement in itself is the essential requirement for any further return to normal living. These patients are cared for by either the nursing staff or by the consultant clinic staff with community nursing follow up in between appointments. Those attending the consultant clinic where the regimen of choice is the high compression four layer bandage system, have their comfort during treatment considered and often pain control is, at least, attempted. They have the additional comfort of thinking that they are receiving the best care possible. Those not attending the consultant clinic assume that their nurses know what they are doing and that there is no other reasonable alternative. They do not have to be entirely content with their condition to use this normalising strategy; they merely need to have reached the conclusion that

they are receiving good care which equates to having pleasant relationships with the professionals caring whom they think are doing everything they can to minimise their problems.

Another aspect of *emphasising the positive* is to view one's life as a healthy one and to define oneself as well. Not one person in this study indicates that she is an ill person.

"I'm well. I'm not cut and messed about like some people are, touch wood. I have no scars or anything. There are plenty of people worse off than me."

"Oh, I'm not ill. If my knees would let me go, I could get up and tear the place apart! I could rip it apart and give it a real good do. I could go outside and do what I wanted to do outside."

"My general health is all right"

"If I weren't healthy, my leg wouldn't be healing"

This approach is an aspect of "creatively balancing resources for health" which McWilliam et al. (1996, p.6) discuss and it is included in Walshe's (1995) "coping by being positive"(p.1098). It is important to note that the majority of the nurses caring for these patients consider them to be ill; this difference in focus typifies the conflict in view between patient and nurse:

"They're not well because obviously they have got a circulation system problem, haven't they? Initially anyway. So they're a patient that is going to have other complications as well."

Another strategy for normalising was *negotiating for comfort*. In this approach the patient attempts to put issues in such a way as to force the nurse into discussion. For example, one patient who had her dressings applied too tightly for her comfort said: "I said to her(the nurse) you make it too tight to walk and it swells a little bit at night, you see, and I feel then I would like to get the scissors to cut it and ease it off a little bit." She is clearly indicating her problem with normal living and assumes the stance of a *Bargain Hunter* looking for a concession. In effect she is stating: "loosen the bandage and I'll comply." The not so veiled threat of tampering with the bandage is the fall back position and indicates that the *Resistor* is just behind the *Bargain Hunter*. In this case, the patient's attempt to gain some control over the situation failed and

unfortunately, soon after, her overall condition deteriorated to the point where she could not longer carry out her threat of tampering with treatment and regaining her rightful role as navigator. Her attempts at normalising and at comfort work fell on professionally deaf ears.

It is not uncommon to find that patients seek an accommodation with their nurses about the tension of the compression bandages in order to gain increased comfort, but so often, as the following quotation indicates, professional deafness and the nursing focus on the ulcer and not the patient drown out the voice of the patient:

“ When that’s on too tight your legs hurt and I don’t care what they say, but they can’t put their legs in my legs in the position because they hurt. Of course I try to tell them, but...I don’t get anywhere with them”

Patients might employ all three strategies: the adapter could also chose to assume a positive outlook and by negotiating for comfort could be a person indicating either a willingness to endure if necessary or to move beyond to a position of greater self direction.

The exceptional person is found who manages most of his care but these are always people who have not been trapped within the system at any point: the young business woman who has to assume her own care because she cannot avail herself of nursing care, the younger man who has a job to do and cannot take time off from his work to attend the nurses’ clinic sessions. These patients might still attend a consultant clinic every few months for overall monitoring and all have to rely on the doctor, usually through his nurse, for prescription of wound care products but they are essentially free of the ongoing nursing management of their care.

Summary

Normalisation is the goal of every patient with an acute or chronic illness. The professional management of the trajectory should enhance the probability of this being achieved as quickly and completely as possible. However, as has been demonstrated, when the trajectory being managed is that of an “ulcer” and not of the “person”, there can be no real hope of successful integration of the chronic condition within the framework of an individual’s unique life. Those

with venous ulcers are not alone in suffering from what are essentially iatrogenic complications. For example, those with psoriasis also face a lifetime of essentially ineffective treatments and similarly remain dependent upon health care professionals:

“The psoriasis sufferer must cope not simply with ‘the biological entity’ but psoriasis under particular forms of treatment. While undoubtedly part of the ‘solution’, therapeutic regimens are equally undeniably part of the ‘problem’”(Jobling,1988, p .229).

Similarly, they must seek to adapt as best they can without understanding their nature of their disease:

“‘What does all this mean?’ Is a perfectly reasonable question. If formally put to medical professionals, answers may not be forthcoming; or if they are, they may be confusing, difficult to understand, or couched in terms far from guaranteed to convey clear information to a lay person. It is scarcely surprising therefore that lay people fall back on a vernacular ‘folk’ knowledge, supplemented by a common sense reading of apparently significant messages or signs conveyed without deliberate intent, by doctors, nurses , and the like... The choice of treatment and its form is potentially a major source of information and a basis for interpretation by patients, relatives and the wider public. ” (Ibid.)

The treatments, like the factors inherent in the condition that drive the individuals to seek treatment, can be viewed as either “intruders” or “enablers”. These are terms coined by Leidy and Haase(1996, p. 84) to explain certain aspects of the reciprocal impact of living with chronic obstructive pulmonary disease. One would be more likely to deem the symptoms of a chronic illness as the “intruders” and treatments as “enablers” but, as in the case of patients with venous ulceration or psoriasis, or any number of other chronic illnesses, the treatments themselves, can be seen to fall into both categories and thus be part of the problem or of the solution.

Leidy and Haase found that “Knowing was the overarching or grand enabler”(1996, p.85.). The knowledge required was both formal and experiential. It was the “principal enabler, helping informants maintain desired levels of performance as they faced the intruders”(p. 88). Given that this is the accepted view in health education one has to ask, again, why the patients fare so poorly in terms of knowledge given from within the health professions. Perhaps the answer lies precisely in that it is information given from within

health professions whose focus is the treatment of pathology; their specialist centred and disease oriented focus is totally in accord with the overall approach to the care and instruction they provide. In order to meet the patients' needs, the health education or patient teaching role, perhaps needs to be divorced from the medical vision of disease and replaced by a personal view of illness. It might be that what the patient suffers from is a lack of professional nursing, for, if nurses were working within the scope of nursing, rather than acting as extensions of medical practice, the patient's responses to his disease, that is, his illness experience, might be both seen and responded to. It could be reasonably argued that the nurse is ideally placed to bridge the gap between medical knowledge, treatment and the needs of an individual to live his life to the fullest extent possible within the constraints imposed by his condition: this is, in effect, what supportive assistance entails.

Chapter 6 Conclusions and implications

This study has highlighted a number of important issues in the management of patients with venous leg ulcers. In concluding, the findings will be summarised and the implications for medicine and for nursing will be presented. The final paragraphs will be devoted to a discussion of what “grounded caring” would be for this patient group.

The essential problem the patients have to contend with is the incorrect handling of their chronic illness trajectories. The initial medical piloting fails to define their pathology at the required condition specific level. As a result, they are prescribed interventions that are often ineffective in managing even their most pronounced symptoms. The custom and practice of referring any patient with a wound to the nurse for ongoing care essentially shunts them off into what Roth(1963) referred to as a “chronic sidetrack” (p.69). Without the definition of their problems, their ongoing treatment by nurses fails to address either their acute symptoms or their chronic illness experiences.

The patients are shifted from medical to nursing care because the doctors lack the knowledge and skill to help them. The categorisation of their problems as “leg ulcers” or “wounds” symbolises their “failure” position in the health care system. Unfortunately for the patients, this relegation to general nursing care rather than effective medical treatment of their as yet undefined condition, does not even assure them of quality palliative treatment. Because the nurses actively seek to heal the wounds of their patients, the patients have a semblance of curative management and often feel that their unquestioning or at least compliant behaviour will achieve the goal they so want: healing and the normality it brings.

The essential role of navigator is one the patients are quite willing to place in temporary abeyance when they seek the expert help of the professional pilot. They do not seek to lose control of their care but when they do, there are simply no reasonable options available to them: their symptoms are distressing and their care is so often managed with complex dressings they could not apply unassisted. In short, once navigational control of the health trajectory is lost as a result of the medical encounter, they are dependent upon their professional carers who act not as supportive assistants, but as

controllers of their health trajectories. The present approach to management is routinely ineffective in dealing with their symptoms, causes marked disruption to their lives and makes them dependent upon professional help. Skilled and capable people enter the surgeries only to emerge as people not trusted to carry out even the simplest of care.

The acute phase

When the individual develops signs and symptoms indicative of a deviation from his normal experience of health, he has to make decisions about management. The alterations from normal health often include such signs as: staining of the skin of the lower leg, prominent varicose veins, weeping lesions, enlarging wounds, the occurrence of exudate, swelling to the lower leg. The symptoms to be assessed might include: aching legs or acutely painful wounds. There is an often prolonged period of self care or navigating. This fact in itself should indicate the level of competence of the individual; he manages ongoing problem solving for periods in excess of a year in some cases. The development of acute symptoms leads him to the doctor. What he seeks in this encounter is quite simple: something to deal with his symptoms and a determination of his underlying problem, that is, an explanation of why this wound has failed to heal.

If the nature of the problem were to be determined as a result of the medical encounter, many of those who have venous ulceration could be assisted with immediate symptom control and returned to navigating their own health trajectories. All that would be required to achieve this end would be instruction in wound care and health education concerning the condition of venous hypertension. With this information and new skills the individual would be able to manage his trajectory within his biography with perhaps occasional recourse to the doctor or nurse for piloting assistance in conditions of uncertainty. However, the patient is not dealt with in this manner and is instead subject to long term and ineffective management.

Managing the chronic condition

Assuming effective management of the acute phase of the trajectory were achieved, the individual would have the knowledge and ability to manage his chronic condition. The health education he might receive from the doctor or nurse would allow him to navigate more safely within the constraints of his condition. In the future he would know how to interpret signs indicative of the onset of another acute phase: deterioration of the skin of the lower leg, an injury to that area, an increase in pain.

Beginning the patient career

The patient begins a career within the system because the doctor fails to provide him with the correct diagnosis. His situation is compounded by the fact that the nurse to whom he is referred for ongoing care knows well that he has a chronic condition and begins to search for the medical diagnosis to guide her treatment.

What she could be doing at this stage, assuming an appropriate diagnosis had been made by the doctor, would be providing nursing care. Her focus should be on the person's reactions to his disease, that is, his illness experience. Appropriate nursing interventions might be directed towards helping him to cope with his particular problems such as: disordered sleep, managing the pain, presenting himself normally in his everyday life, dealing with the odour from wound discharge, finding acceptable forms of compression to manage oedema. In addition, she could focus on his specific learning needs in relation to self care by helping him to learn about his condition, the action and safe use of analgesics, signs indicative of wound infection, the purpose of leg exercises, adapting the way he carries out his usual tasks to minimise prolonged strain on the venous system, how to bathe safely with a dressing in place. These are only suggestions and by no means exhaustive lists of nursing interventions.

The individual begins a patient career quite simply because the doctor fails to fulfill his role and the nurse attempts to undertake this diagnostic function. Her attempts to compensate for the medical deficiencies in the patient's' care compromise her role in relation to the patient, move her beyond

the scope of her competence to practice, endanger the patient and fail to address his needs.

Before exploring the care these patients would like to have within the health system, the implications of the current trajectory management for medicine and nursing will be considered.

Implications for medicine

The first and core issue is the lack of medical definition. The chief medical officer, Kenneth Calman, addressed his profession in 1994 and he reminded his fellow doctors that the essential difference between their role and that of others in health care was that they are responsible for making the medical diagnosis:

“There is one aspect of practice of profound importance which is generally carried out by doctors—that is making a diagnosis and assessing its consequences. The implications are crucial. Firstly, the consultation, the accumulation of information, the making of a diagnosis, and setting out the prognosis and possible treatments make up the basic building blocks of health care and resource allocation. Further, a key part is the communication of the diagnosis, prognosis and treatment to the patient, or to the community. Making a diagnosis is not simple and straightforward even when the name of the “disease” is well recognised. Social and family implications are crucial, emphasising the holistic nature of the concept and of patient care. It is a person with an illness and not just a label, and the wider implications of the “diagnosis “ need to be emphasised...others may take the lead role in following through treatment...but the fundamental issue remains the diagnosis, its communication, and the setting out of a plan of action, agreed with the patient or the community on the management of the problem”(Calman, 1994, p.1141).

He recognises that “diagnosis” can have many meanings ranging from a “working hypothesis” to “histological confirmation” and he accepts that there will be uncertainties but he places the responsibility of communicating these uncertainties with the doctor and he reminds his colleagues that:

“Learning to live with uncertainty as a patient is not easy and, as the progress of the disease process evolves, continuing support and explanation are required. However, this emphasises again the central nature of the diagnosis, its consequences in health care and the need for a holistic approach” (Ibid.).

He hoped to stimulate a full debate “on the purpose of medicine and its basic values” that would effect medical education in a time of change.

Also in 1994, the president of the British Medical Association and the editor of the British Medical Journal (Morrison and Smith, p.1099) wrote of their vision of the future of medicine. They discussed the five driving forces they saw behind the transformation of the profession: economics, sophisticated consumers, new technology, ethics and the shifting boundaries of health and medicine.

Of these factors, the economic pressures of the “big ugly buyers” are perhaps the most powerful change agents in the present cost constrained climate. The demand for “evidence based medicine”, which was a new phrase in 1994 has become increasingly familiar and the authors suggested then that “all will know it by the millennium”(Ibid.).

The forces unleashed by the “big ugly buyers” in this purchaser-provider health system, are however, not always grounded in good medical practice nor the patients’ best interests. Bosanquet (1992, p.44-45) using 1990-1991 estimates of nursing, medical and dressing costs calculated that the total cost of care for patients with leg ulcers in Britain was between £280-408 million. The data from the Lothian and Forth Valley study show just how ineffective the expenditure of money is in terms of achieving healing and maintaining it.(Callam et al. 1987a). This is costly care and many authorities are targeting it as an area of potential cost savings. Freak et al.(1995) audited the costs of leg ulcer care in Stockport and Trafford health authorities and concluded that “large resources are being expended on maintaining rather than healing venous ulcers in this country”(p.135). Note how healing the obvious medical problem is the target they appear to value and not the management of illness trajectories to minimise disruption to the patients. They found little change in the management patients with leg ulcers from the time of the Lothian and Forth Valley study in 1985. Their suggested solution overlooks the essential importance of determining the actual nature of the pathology in patients who present with leg ulcers, and it disregards the core function of medical diagnosis advocated so strongly by Calman. Similarly, it fails to recognise the chronic nature of the problem for most of the sufferers: the focus is, as always, the most

superficial aspect of the problem. The way forward, as Freak et al. (1995) view it, lies in the establishment of more community based , nurse led, leg ulcer clinics. For the suggestion to be made that nurses could provide an adequate screening or the definitive determination in community clinics by simply making the most basic assessments is to underestimate the complexity of the problem and to deny the possibility of cure to that small but significant number of patients in whom the only pathology might be saphenous or perforator incompetence. Yet, this is exactly what is being suggested by Freak et al. when they state that now that the initial audit has been completed, they intend to establish "five community leg ulcer clinics across Stockport Health Authority, with nurses trained in all aspects of leg ulcer assessment and management." They state quite clearly that the drive to establish these clinics is the "over 70% complete healing within 12 weeks of treatment"(p.136) and the cost savings. They fail to mention the serious rates of ulcer recurrence found with this approach in the Charing Cross study (Moffatt et al, 1992). Instead they express some surprise that most of the patients are "thought" to have venous ulcers but are not treated with compression. Given the nursing dilemmas caused by the lack of medical definition seen in the present study findings, this result is not surprising: the nurses must proceed with care and that means lower forms of compression until the nature of the disease is better known. In short, the "big ugly buyers" referred to by Morrison and Smith, may be leading to a continuance of inferior forms of care that leave the patients trapped in a cycle of suffering based on medical ignorance, economic factors, and nurses who fail to appreciate their accountability or the nature of their profession. Unless doctors come to realise their responsibilities in relation to this group of patients, there will be little hope for the patients who present in their surgeries with these problems.

The rise of sophisticated consumers may change the face of medical practice eventually but it would appear to be a slow process. Morrison and Smith(1994, p. 1099) suggest that as patients become more educated, a change in medical practice will be forced upon the medical profession. It is rather sad however, that the profession of medicine requires such a counter force to be applied by the articulate and well read before it will reconsider the

doctor-patient relationship, which is "at the heart of medicine"(Ibid.). The assumption that patients can effect change within the system may be true but it is by no means easy. Arksey(1994), as an example, discussed the problems of those with repetitive strain injury in getting the medical profession to see it as anything other than a nonsense. It was, as has so often been the case when patients' needs have been unrecognised by health professionals, the collective action of a self help group that forced it onto the medical agenda.

Essentially what is required is for the doctors to act as doctors and carry out that essential component: the medical definition of disease. If they were to act as pilots, that is, as experts in the short term who needed to consult the permanent navigator in order to give any sense of direction beyond the immediate period, a more equal relationship might result. Perhaps if they even, after diagnosis, recalled these patients from the care of the nurses from time to time to reassess both how the condition was responding and how the patient was faring under their mutually agreed treatment, better biographical results would be obtained. There is certainly a need for further education of the medical practitioners because, as has been shown, their appreciation of this group of disorders is so limited that they speedily abdicate responsibility and await requests from their nurses for prescriptions.

Implications for nursing

The implications for nursing are numerous from the present study. The primary problem appears to stem from an unquestioning acceptance of inappropriate medical referrals. The need for continuing professional education is indicated in a number of areas: in relation to the scope of professional practice and accountability, pain management and advocacy, nursing diagnosis, wound care and the management of chronic illness. Custom and practice have provided a ritualistic way of handling this group of patients and it is unquestioned by the vast majority.

That the nurses have not the technical nor professional competence to handle the tasks they have been given or have assumed in relation to the care of these patients is obvious both from this study and from the literature reviewed. That the nurses routinely attempt to carry out a diagnostic role and

that they control prescriptions even though the doctor must sign the scripts, is also evident. The fact that many nurses express pride in the fact that they have been asked by their doctors to handle something the doctors themselves are incompetent to manage indicates a lack of appreciation for their unique role. The nurses, are in effect undertaking the tasks that the doctors do not want or cannot be bothered to manage, or fail to see as their own. The Briggs Report(1972) recommendation seems apt in this situation:

“We do not consider, however,...that the future of the nurse or midwife, lies in her becoming a junior medical assistant... If the nursing and midwifery profession were to be expected to undertake a greater proportion of the more frequent, boring, inconvenient or time consuming of the doctor’s tasks, because of a false assessment of the similarities between the two professions, then the caring function, to which we attach such basic importance, could be jeopardised” (para.150, p.47).

That caring element is precisely what is at risk when the professional boundaries are overstepped because when nurses begin to practice medicine they lose their core focus: the patient as he responds to his illness. The job of the nurse, as seen by the Committee on Nursing (Briggs, 1972, para. 137, p.44) was stated thus:

“Whether nurses are in the hospital or in the community...their central role is to ensure the care and comfort of the person being nursed, to maintain oversight and coordination of that care and to integrate the whole—both preventive and curative—into an appropriate social context.”

The views of the Committee are very close to those of Corbin and Strauss(1992, p.20-21) in terms of the core role:

“helping clients to shape the illness course while also maintaining quality of life...through the provision of a type of nursing care termed ‘supportive assistance’...directed at assisting with the prevention of illness and, should illness occur, with the proper management of the chronic condition, while giving consideration to biographical needs and the performance of everyday living activities...Specific nursing actions include direct care and—just as important—teaching, counseling, making referrals, making arrangements, and monitoring. Since cure is not possible, the supportive assistance should be seen as an ongoing process that includes ‘trajectory’ orientation. It should shift in nature in accordance with the changes in clients’ illnesses and families’ living conditions, while keeping in mind where the clients have come from and where they might possibly go.”

The "caring" role has been seen to be in need of further development with regard to this group of patients. It might be that the focus on acute care will lessen as more nurses graduate from the new Project 2000 programs where there is increased emphasis on the concepts of health and community. Likewise, the Post Registration Education and Practice(PREP) requirements that came into force on April 1st 1995 might help as they require each nurse to undertake five days of study or equivalent every three years in order to maintain registration. Although these study periods must be directly related to one's professional practice there is, of course, no guarantee that any time will be spent by District Nurses and Practice Nurses, or nurses in dermatology wards, on any of the above issues.

The moves towards a more extended role of the nurse are perhaps of some concern in the light of this study. Hopkins, (1996) reported on a "skills development programme"(p.35) that is being undertaken in Sheffield, the purpose of which is to train nurses in such procedures as: venepuncture, recording ECG's, intravenous cannulation and intravenous drug administration, male catheterisation, and defibrillation. It is of interest that while the "continuity of patient care" is said to be the driving force behind these changes the tasks chosen are ones that usually would be carried out by doctors or technicians; later in the article it is admitted that: "The main objective is to reduce the number of hours worked by junior doctors"(p.36). Extreme care needs to be used in using the "continuity of care" argument to extend the role of the nurse, because by the same token one could argue that she learn to take the x-rays or take on the role of dietitian, occupational therapist, physiotherapist, social worker—the list could be endless. The argument that it is safer for the patients to have properly trained nurses, as opposed to haphazardly trained medics (Ibid.) to carry out these procedures, is likewise, flawed. The fact that some nurses may be better than doctors at some things, or vice versa, does not amount to a reason for the professional absorption of inappropriate tasks.

This expansion of role beyond that traditionally held to be "nursing" is also seen in the arrival of limited nurse prescribing. Although only being carried out in pilot sites at present, the practice is beyond the usual scope of practice. Nurse prescription of wound dressings in the Bournemouth and Christchurch

Hospitals NHS Trust has been reported by Lockyer-Stevens and Bowden(1995). They argue that the traditional practice of having dressings prescribed by medical staff at the request of the nurse is an unsatisfactory arrangement because:

"A dressing could be applied to a wound by a nurse without a correct assessment of the wound. Doctors often prescribed dressing items with which they were not familiar...Time was wasted waiting for prescriptions to be written and signed by a doctor, resulting in delay in treatment"(p.697).

Again, this seems an unusual basis for extending the nurse's role. In their pilot study of nurse prescribing they found that "only 64% of dressings selected were appropriate to the wound at the time of prescription"(p.701) which begs the question of the nature of the education these nurses had before extending their role. In the "Nurse Prescribing Final Report" (Dept. of Health,1991), it was noted that the financial benefits of nurse prescribing would be minimal either from time saved or staff salary costs. The authors indicated however, that there would be training costs incurred by each health authority taking up this option. Having liaised with the United Kingdom Central Council for Nursing, Midwifery and Health Visiting, they stated that the costs would involve a two day training at approximately £60.00 per trainee(p.31) and this leads one to think that it would be only the administrative concerns that would be covered: to include the indications for use of even the limited nurse formulary, would require much longer and cost appreciably more.

The extension of the nurses' role into leg ulcer diagnosis is certainly not one that nurses are competent to undertake without considerable further training. One needs to question if this is good use of nurses' time and whether, like many other laboratory or diagnostic tests, it should not be a function undertaken by a specially trained group of technicians. The nurses themselves seem very keen to pursue an autonomous role within wound care, including leg ulcer management but that seems more to reflect their lack of clear vision about the nature of nursing and their professional insecurities.

Grounded caring

Whereas the doctors are failing to carry out their central function and the nurses appear to be navigating for the patients in an inappropriate and sometimes quite incompetent manner, the patients have a very clear idea of the care they require. If the patients could be heard within the context of care they could help doctors and nurses resolve a number of professional dilemmas and this could also result in their needs being met. All the patients need is competent carers who are not professionally deaf to them as people. The patients seek three things in their contact with their health professionals: expertise that is reflected in information given to them about the nature of their problem, expertise in pain and symptom management, and perhaps above all, a caring attitude.

Patients should be able to expect that the professionals are experts in matters relating to health or be able to obtain the information they require. That they cannot expect this in the present management of their care is a key problem. The solution would appear to be fairly straightforward: continuing professional education. However, in order to obtain it, an awareness of professional inadequacy and the motivation to overcome it would be required and what is seen is a drive to maintain the present pattern of care and to make it cheaper, not better.

The patients should also be able to expect competent pain and symptom management from their doctors and nurses. However, pain is a notoriously difficult area for both professional groups. It is a subjective phenomenon that can only be approached through the exploration and acceptance of the patient's experiences and this area is the missing aspect of the care of the patient with a venous ulcer: his biography, his experience, his needs as a person are all generally overlooked. Both doctors and nurses have a professional duty to assist those in need and to do no harm. The Code of Professional Conduct of the U.K.C.C (1992) states quite clearly that it is the nurse's duty to: "act always in such a manner as to promote and safeguard the interests and well-being of patients" and "to ensure that no action or omission on your part, or within your sphere of responsibility, is detrimental to the

interests, condition or safety of patients and clients.” Leaving patients in pain prolongs their suffering. Failing to deal with pain as an integral component of professional medical or nursing practice quite simply contravenes the basic tenet of malfeasance because pain has detrimental physiological and psychological consequences.

Why are the patients left in pain so often? One answer that has been fully explored in the previous chapter is that it is used as a clinical indicator of diagnostic significance and not assessed as an holistic experience. Another explanation is that there is widespread ignorance of palliative care methods in both professions. This amazing fact stems from the background of both professional groups. They have been trained in hospital settings, where accountability for pain management is not the central focus: “many, if not most, medical and nursing tasks have nothing to do with pain” (Fagerhaugh and Strauss, 1977, p. 19). In some areas they are expected to attend to pain: on wards where patients have terminal illnesses or in hospices, for example, and it is important to appreciate that there is a sentimental order to work in various situations and that it is the expected pain trajectory that will be managed: the patient with a venous ulcer is not expected to have pain. The staff who deal with patients with venous ulcers are therefore not organised nor psychologically set to handle it. “In general, the nursing and medical staff know little or nothing about a patient’s pain trajectory, other than the evolving portion of it” (Fagerhaugh and Strauss, p. 23). Their focus on the immediate that would perhaps be more understandable in acute care, severely limits the care they can see as relevant in chronic care.

The patients problems in getting the health professionals to hear them is therefore quite involved and perhaps amenable to manipulation through continuing education. For a patient to change the sentimental order is a difficult task as has been discussed. However, again, change takes place in response to need, and as long as the situations of these patients can be interpreted by health professionals and not as they are experienced by patients, those who control the interactions will be able to define them.

When it became obvious through interviews that the patients were not receiving the care they would have liked, a question was added to each

subsequent interview: "If you taught nurses about how to care for people who have your problem, what would you tell them?" They asked for a chronic illness perspective: patience, information, caring that was obvious in a listening presence, gentleness, kindness and inclusion in trajectory planning. The human dimension is the one most frequently overlooked and clearly desired by the patients.

"Patience! Because it is so slow to heal. You've got to have patience—patience with them and patience with the patients. It's a slow job."

An acute care focus in a chronic situation is counterproductive and potentially dangerous. To attempt to hurry the healing in a wound that is a manifestation of chronic pathology is to cause considerable disruption to the lives of the patients. The lady quoted above had the experience of being blamed for the lack of progress in wound healing. She came to accept the chronic nature of her problem before her nurses.

The importance of being treated in a caring manner comes through so often in the interviews and this above all is valued: being heard as an individual with particular need instead of being treated as a pathological category:

I would want an understanding person, you know, someone who will listen to you because obviously everybody's ulcer isn't the same and probably there's some little thing that they can do for you that will make it more comfortable. Try to make sure that everything is comfortable for the patient. And the nurse always sees that the bandage is at the right tension. Apart from that, I can't think of anything else—and I would always have time to listen to patients—you need an understanding person, someone who will listen to you."

The patients ask for that personal element when they think of the ideal nurse, that is, the nurse they would want to care for them.

They are fearful or anxious and need information in which to place their experiences and deal with their uncertainty:

"To tell the patient for a start, what they are going to do to you because the patient needs to know. There are so many nurses who go into it and think: 'Oh well, she's got an ulcer; I'm going to dress it' and

they don't seem to tell you beforehand what they are going to do and I think that's important. I like the doctors in the hospital—they tell you what they are going to do. I've been in hospital a few times. I've had a breast off and I've had a hysterectomy and they just say: 'Oh, it's a hysterectomy for you' and they don't tell you what they are going to do—and you wonder...."

They want to be listened to and have their contributions to care valued, not summarily dismissed unless there is supporting evidence from a fellow health professional to corroborate their views:

"I should say: 'Don't go with a stick your hand all the time and brow beat people. Let them just tell you about them, about how they are feeling. Today they put a foot on the rung of the ladder and then everybody's down and they are up there. That's my idea—I think everybody's too self opinionated nowadays—they think they know better than everybody else."

"I should make sure that I told them what I was using—what I thought I was allergic to. They were putting them tea bags (Actisorb) on—well, it went awful—terrible—it doubled its size in a fortnight. I told them to write it down! I gave nurse a paper and said 'Write it down'. Then later—if they get a little bit annoyed about it —if you tell them anything—well you bring out the paper and they say 'oh yes, you can't put that on it; you're allergic; and then they agree with you."

"With Mrs. L I know she knows what she's doing. But when she's away I couldn't tell *them lot (the other nurses)* what to do. Mrs L says: 'I don't see why not when you know what should have been done' but I said that I don't think they would have been pleased at me saying what I wanted them to do with it."

They want care that meets their individual needs for comfort in terms of presenting themselves and feeling comfortable physically:

"Come a bit oftener if they could because that's how you feel when they are hurting very bad—you think: 'Oh if only they were done every other day'. You see it used to be Monday and Friday, well it is Monday and Friday now—but then you are Saturday and Sunday. Like that's just two days between but then its three,"

The gentle approach is something that all patients can assess and often they did not rate their nurses well in this respect:

"A bit more caring. I mean they are very dedicated but you had one and she was a bit slap happy and it hurts. But they are all very good, but some of them could be a little more gentle when they are wrapping it up—not so much like wall papering! And it really hurts!"

"I wouldn't say 'rough' is the word (said the wife of the patient) but she wants to do it HER way and after all it's his leg! He does, when we have a new one, tend to tell them what to do and there is one that doesn't like to be told what to do. So in the end, he gives up and just sits back—but in the end I think it is painful because she is so quick with it."

"Be gentle with them because if somebody kicked your leg like that—if somebody roughs it up—it can be very painful to touch."

The patients agree with the words of Miss Nightingale(1859) who noted:

"In watching disease, both in private houses and in public hospitals, the thing which strikes the experienced observer most forcibly is this, that the symptoms or the sufferings generally considered to be inevitable and incident to the disease are very often not symptoms of the disease at all, but of something quite different—"(p.1).

The disease causes a certain group of physical symptoms and signs, but the suffering arises from the context of care, from the want of recognition of and respect for the navigator. When he is displaced from his central position, then inadequate care and inappropriate treatment are easily prescribed in an approach that fails to see the individual.

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